

Compassionate communities:

An implementation guide for community approaches to end of life care

July 2018

Introduction to compassionate communities

Compassionate communities are a core part of public health approaches to palliative care, end of life care and bereavement. The term was coined by Allan Kellehear in the mid-2000s to describe communities which play a much stronger role in the care of people at end of life and their families and carers through illness, dying, death and bereavement.¹

Compassionate communities draw from the [Compassionate City Charter](#), which 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.”

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.

Public health approaches to palliative care, end of life care and bereavement, including compassionate communities, address these challenges. They draw from the World Health Organization’s [Ottawa Charter for Health Promotion](#)² to focus on early intervention and social approaches to the problems and experiences of dying. They encourage service providers, people at end of life, families and communities to seek ways to promote emotional, social, and spiritual well-being, as well as physical health.³ 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, recognising that marginalised populations may have less access to services and worse outcomes at end of life than others.⁴

Surveys in Australia show that over 70 per cent of people would rather die at home, but most die in hospital instead.⁵ The increasing focus on the role of primary care and health and community services, and community settings for delivery is consistent with an increasing preference by people at end of life to die in their homes, whenever possible.

Compassionate communities are most effective when they are part of broader public health approaches to palliative care, end of life care and bereavement. While this guide focuses on compassionate communities, other elements of public health approaches are also important, including palliative care, health and social services, and support from civic institutions, such as schools, workplaces, and faith-based organisations. All of these elements are essential to improve quality and continuity of care for people at end of life and address issues of access to care.⁶

Since the first compassionate communities emerged in Australia in the mid-2000s, the movement has grown both in Australia and internationally, particularly in recent years. Today, there are many examples of compassionate communities around the world and a growing body of research on the benefits of compassionate communities to individuals, communities and health systems.

“A city is not merely a place to work and access services but equally a place to enjoy support in the safety and protection of each other’s company, in schools, workplaces, places of worship and recreation, in cultural forums and social networks anywhere within the city’s influence, even to the end of our days”.

Compassionate City Charter, Allan Kellehear

About this implementation guide

The purpose of this implementation guide is to provide an information resource on how to initiate, grow and sustain compassionate communities approaches. It draws from literature and best practice on compassionate communities and public health approaches to palliative care, end of life care and bereavement.

This guide is designed as a resource for:

- Individuals and community groups that are interested in initiating and growing their own compassionate communities.
- Other organisations that are interested in using community development approaches to support the initiation and growth of compassionate communities, including; community organisations, health and social service providers, residential aged care facilities, not-for-profit organisations, universities, civic institutions and others.

It provides principles, steps and information resources to help guide the establishment, implementation and measurement of compassionate communities.

This guide adopts a broad interpretation of compassionate communities. Much of the information in this guide is also relevant for broader public health approaches to palliative care, end of life care and bereavement.

There are six parts of the implementation guide:

	<u>About compassionate communities</u>
	<u>The underpinning principles guiding change</u>
	<u>Roles for different stakeholders</u>
	<u>Key steps for implementation</u>
	<u>Measuring success</u>
	<u>Useful resources</u>

Acknowledgement

The development of this implementation guide has drawn on thought leaders and published literature on compassionate communities and public health approaches to end of life and palliative care. It also reflects the insights generated through a series of case studies on existing compassionate communities and public health approaches to palliative and end of life care in Australia, New Zealand and the United Kingdom.

See further [Useful resources](#) for a summary of the material that has informed the development of this implementation guide.



About compassionate communities

What are compassionate communities?

Compassionate communities operate as part of a broader public health approach to supporting people at end of life, their families and carers. They are described by Abel, Kellehear and Karapliagou as “naturally occurring networks of support in neighbourhoods and communities, surrounding those experiencing death, dying, caregiving, loss and bereavement.”⁷ 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.”⁸

Compassionate communities usually involve people in the same geographic location but they may also involve families, neighbourhoods, faith groups, local organisations, workplaces and groups of people that share similar experiences, such as Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse (CALD) populations and lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ) communities.⁹ These communities:

- Care for people in all phases of end of life, from illness through to bereavement for family, friends and carers of people who have died – including people who are vulnerable or marginalised.
- Respect and respond to the needs and wishes of the dying person and their families, including social, physical, psychological, cultural and spiritual aspects.
- 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 initiated and grown through community development approaches.

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.

They are generally led by non-expert carers and compassionately active people from the community who work together to provide care and support to people at end of life and their families. This might be through cooking meals, caring for children, spiritual care or assisting people to access health services.

Some compassionate communities are grown organically by citizens with little or no external assistance. Others are initiated through partnerships between communities and formal organisations, such as health and aged care providers, universities, schools, local governments or not-for-profit organisations. These examples generally involve the use of community development approaches to increase awareness about death and dying and develop the capacity of people in the community to care for each other.

A growing number of palliative care services are working closely with families and communities to deliver holistic care in people’s homes. These services adopt a public health approach to care and display many of the positive attributes of compassionate communities.

While compassionate communities are diverse and locally responsive, the fundamental underpinnings remain common. Compassionate communities involve the activation of community members to care for each other. They draw on community strengths, resources and resilience to deliver more holistic care to those experiencing death, dying, caregiving, loss and bereavement.

Compassionate communities recognise that people at end of life and their families have better experiences and outcomes when health professionals and civic institutions empower and work with communities through a public health approach to palliative care, end of life care and bereavement.

What do compassionate communities do?

Compassionate communities support people at end of life and their families in many ways. They care for people, assist people to live in their homes, connect people to services, raise awareness about end of life issues and develop the capacity of others in the community. While each community adopts its own approach, there are some common activities of compassionate communities and public health approaches to palliative and end of life care.

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.

What are the benefits of compassionate communities?

Research indicates that there are many potential benefits associated with compassionate communities. This includes benefits for people at end of life, their families and carers, communities, health and social care professionals, and health and social care systems.

It is important to note that many of these benefits are attributed to a combination of compassionate communities and other approaches to improving palliative care, end of life care and bereavement. Research shows that the best outcomes are achieved when compassionate communities are implemented as part of a comprehensive public health approach. This is critical to achieve system- and population-wide improvements to end of life and bereavement outcomes.¹⁰

The benefits listed below come from published research and case studies of compassionate communities.

Stakeholders	Potential benefits*
 <p>People at the end of life</p>	<ul style="list-style-type: none"> ✓ Improved quality of life and wellbeing¹¹ ✓ Reduced stress and anxiety, which is linked to reduced experiences of pain¹² ✓ Reduced fatigue and feelings of isolation¹³ ✓ Increased death literacy and willingness to have conversations about death and dying¹⁴ ✓ Increased awareness of and access to palliative care and other services, including for marginalised populations¹⁵ ✓ Increased confidence in asking for assistance and the ability to find resources¹⁶ ✓ Reduced palliative care-related hospital admissions and reduced lengths of stay in hospital¹⁷ ✓ Increased likelihood of being cared for and dying in place of choosing, including at home¹⁸ ✓ Personal growth and learning, including greater appreciation of self and identity, and improved sense of belonging¹⁹ ✓ Improved cultural responsiveness and appropriateness of care

Stakeholders	Potential benefits*
 <p>Families and carers of people at end of life</p>	<ul style="list-style-type: none"> ✓ Improved quality of life and wellbeing²⁰ ✓ Increased death literacy and willingness to have conversations about death and dying²¹ ✓ Reduced stress and anxiety ✓ Reduced burden of care on informal caregivers through support in day-to-day tasks²² ✓ Improved bereavement outcomes²³ ✓ 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 dying²⁴ ✓ Growth of social capital and capacity building ✓ Growth of formal and informal partnerships ✓ Greater community self-sufficiency and sustainability through strengthened relationships²⁵ ✓ Improved access to resources,²⁶ including access to information and local services²⁷ ✓ Increased awareness of palliative care services²⁸ ✓ 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 families²⁹ ✓ Increased sense of community inclusion and cohesion³⁰ ✓ Increased helping and caring behaviour by community members³¹ ✓ Increased number of community-driven and -led activities³² ✓ 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 community³³ ✓ Reduced care burden on health and social care professionals³⁴ ✓ Reduced likelihood of compassion fatigue and secondary traumatic stress of staff³⁵ ✓ Increased discussion about the non-clinical needs of a person at end of life³⁶
 <p>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 care³⁷ ✓ Development of an active and engaged palliative and aged care environment ✓ Growth of formal and sustainable partnerships ✓ Increased equity and sustainability of care through addressing issues of access, equity and quality of palliative and end of life care³⁸ ✓ Reduced palliative-related hospital attendances and emergency admissions³⁹ ✓ Reduced palliative-related length of stays in hospital⁴⁰ ✓ Reduced costs of care per patient⁴¹ ✓ Reduced requests for formal palliative services and acute (hospital) services ✓ Increased organisational capacity in local government on end of life issues for the community⁴²

**These benefits may be attributed to a combination of compassionate communities and other approaches to palliative care, end of life care and bereavement.*



The underpinning principles guiding change

There are five underpinning principles that can guide and facilitate the development of compassionate communities. These principles are adapted from the [Ottawa Charter for Health Promotion](#) to apply specifically to compassionate communities and whole-of-community approaches to supporting people at end of life. While the focus of this guide is compassionate communities, many of these principles can apply to broader public health approaches to palliative care, end of life care and bereavement.

Within each principle, recommended actions provide more guidance. These principles and recommended actions are not intended to be a checklist – note all will be relevant to everyone and they will apply differently depending on who is involved and the scale and scope of activity planned.

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

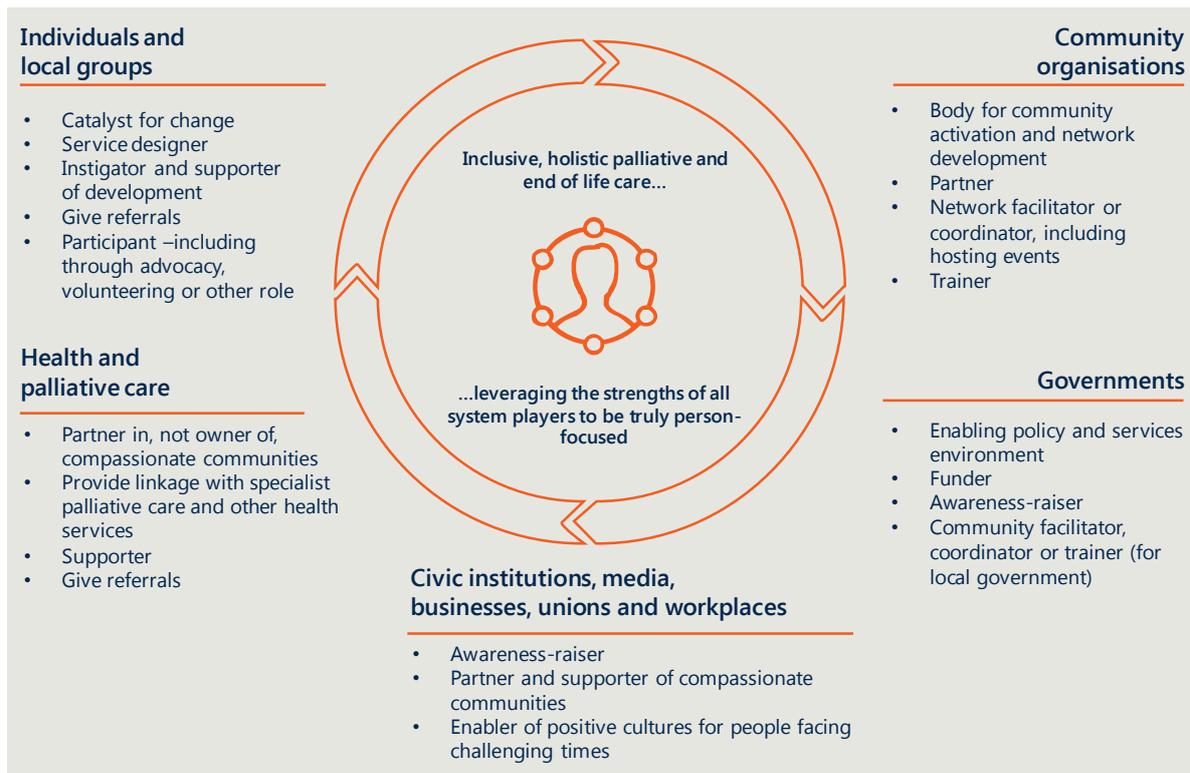
- Develop a system where individuals, families, carers, communities, social, health and aged care services can collaborate to deliver integrated support
- Focus on what matters to people at end of life and their families, including what is important to their quality of life and their preferred place 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.



Roles for different stakeholders

Building impactful and sustainable compassionate communities requires all parts of the community to play their part. Action can be led from anyone, at any level.

- **Individuals and local groups** often provide the catalyst for change (either through instigating action or communicating unmet need). Individuals and local groups must be central in designing a response that is needs-based and person-focussed, delivering initiatives, and driving ongoing development, evolution and sustainability.
- **Community organisations** facilitate community access, activation and development, can provide support, co-ordination and training, and can offer access to facilities and other resources.
- **Health and palliative care service providers** are an integral component in a compassionate community. Specialist, palliative care, hospital, general practice, primary health and aged care services all have a role to play. Service providers must work in partnership with communities, leveraging each others distinct expertise, to deliver a truly person-focused experience to end of life and bereavement that makes best use of available resources.
- **Local, state and territory, and national governments** create the supportive and enabling environment for compassionate communities to thrive. Local government may also play a more active role in community facilitation, development and sustainability.
- **Civic institutions (e.g. schools), media, businesses, unions and workplaces** raise awareness about end of life issues, can offer support and access to resources, and create positive cultures for students, employees and others that are affected by illness, dying, care-giving and bereavement.





Key steps for implementation

Implementation of compassionate communities will not be uniform – each will be driven by the priorities and resources available within specific communities. Implementation involves a range of activities to plan, initiate, grow, sustain and review compassionate communities. The [Useful resources](#) section of this guide contains further resources and toolkits on implementation and community development.

This guide identifies **five key steps** to implementation. In practice this process will not be linear. They can be used to initiate new compassionate communities or to grow and sustain existing ones. They are largely based on evidence-based approaches to community development. Community development and capacity development can be resource-intensive and often require external funding, particularly in the beginning.

1 Identify needs of individuals and local communities

- Speak to community and individuals to understand care and bereavement needs
- Identify existing community assets and strengths, including the existing organisations, services and networks that are already in place, and where there are gaps.

2 Confirm purpose and desired outcomes

- Given the needs within the community, identify the assets and strengths that can be leveraged, and the gaps that need to be filled
- Confirm the outcomes you hope to achieve through the project – test these with community and individuals and be willing to adapt. If outcomes are not aligned, community development and activation will not occur in a sustainable way.

3 Design and plan

- Support community to drive design of the elements and activities of your compassionate community that will deliver on the purpose and desired outcomes
- Learn from other compassionate communities nationally and internationally
- Test and iterate with people at end of life and their families and carers, community members and partner organisations
- Always look to build on existing assets, don't duplicate and avoid starting from scratch where possible
- Identify any available funding sources – these can range from community donations to government grants, and don't always need to be big to make a difference.

4 Implement

- Start small and get started - build from successes and learn from mistakes
- Develop capacity and grow the network of people, organisations and services that can implement
- Be opportunistic – take advantage of emerging opportunities and enthusiastic supporters
- Communicate creatively and broadly – consider multiple mediums and role for partners (e.g. health services may be able to communicate through their patient lists).

5 Understand and improve

- Track progress and measure success (see [Measure Success](#)), but don't try to measure everything
- Understand what has worked and why, and what needs improvement
- Celebrates success, don't be afraid to acknowledge mistakes, and make changes.

Aspiration: Communities that publicly encourage, facilitate, support and celebrate care for one another during life's most testing moments and experiences*

**Adapted from the Compassionate City Charter*



Measuring success

Measuring outcomes and benefits is a core part of community development. Compassionate communities are no different. Understanding what activities are working well, what ones are not and why is critical to building the evidence base for compassionate communities and driving continuous improvement.

Measuring success should not be a heavy burden. Community initiatives often operate with high levels of volunteer support and limited resources, while university and government initiatives often have sophisticated monitoring and evaluation frameworks. Efforts to measure success should be proportional to the size and nature of initiatives to maximise insights while minimising burden and diversion of resources.

Individuals, communities, organisations and health systems are all potential instigators as well as beneficiaries of compassionate communities. The table below provides a set of questions to help measure and communicate success. People and organisations may wish to use some or all of these questions.

Who will benefit?	How do we know we have been successful in the short term?	How do we know we have been successful in the medium and long term?
 People at the end of life	<ul style="list-style-type: none"> • More information available about resources to support end of life care in the community • More people accessing information and support 	<ul style="list-style-type: none"> • Increased likelihood of being cared for and dying in place of choosing, including at home • Improved cultural responsiveness and appropriateness of care • Reduced social isolation and experience of loneliness
 Families and carers		<ul style="list-style-type: none"> • Reduced fatigue and isolation for carers / reduced care burden • Improved bereavement outcomes
 Communities	<ul style="list-style-type: none"> • Increased volunteering (fundraising, care giving) • Increased number of community activities acknowledging death (memorial services, art projects, Dying to Know Day, Death Café etc.) 	<ul style="list-style-type: none"> • Increased community capacity to care for people in all phases of end of life (including bereavement) • Increased death literacy • Increased awareness of community resources, including palliative and end of life care resources • Increased community social capital and cohesion • Increased partnerships between communities, service providers, civic institutions and others • Self-sustaining community activity
 Broader health, aged care and social care systems	<ul style="list-style-type: none"> • More Advance Care Plans are in place • Transparent and formalised organisational commitment to community participation and engagement 	<ul style="list-style-type: none"> • Reduced palliative-care related emergency visits • Reduced unplanned hospital admissions and reduced average length of stay in hospital • Increased staff motivation and morale • Increased organisational capacity in end of life issues • End of life issues are embedded in core business



Useful resources

There are many resources already in place that can help you develop and implement compassionate communities and public health approaches to palliative and end of life care in your area. A selection of resources is provided below. There are many other resources outside of this list available online.

Examples of compassionate communities and related public health approaches

The examples list below include related approaches to public health that support compassionate communities, such as community-based palliative care services that empower and have a strong connection with the local the community and awareness-raising initiatives.

Name	Location	Website or resource
Australian examples		
National Compassionate Communities Practice Forum	Australia	http://www.thegroundswellproject.com/national-compassionate-communities-practice-forum/
Dying to Know Day	Australia	http://www.dyingtoknowday.org/
The 10K Project	New South Wales	http://www.thegroundswellproject.com/10k-project/
Reflected Legacy	New South Wales	http://www.thegroundswellproject.com/reflectedlegacy/
Festival of Remembrance	New South Wales, Northern Territory	http://www.thegroundswellproject.com/past-projects/
Compassionate Communities: A Tasmanian Palliative Care Policy Framework 2017-2021	Tasmania	http://www.dhhs.tas.gov.au/palliativecare/tasmanian_palliative_care_policy_framework_2017_-_2021
The Tasmanian Palliative Care Community Charter	Tasmania	http://www.dhhs.tas.gov.au/palliativecare/tasmanian_palliative_care_community_charter/the_tasmanian_palliative_care_community_charter
Calvary School Health Promotion Program	Victoria	https://www.calvarycare.org.au/public-hospital-bethlehem/services-and-clinics/school-health-promotion/
Culturally Responsive Palliative Care Program	Victoria	http://eccv.org.au/library/Culturally_Responsive_Palliative_Care_Strategy_2013-2015_Final_Evaluation_Summary.pdf
It Takes a Village – Macedon Ranges	Victoria	http://palliativecare.org.au/exceptional-care
Shannon's Bridge	Victoria	https://www.shannonsbridge.com/
Strengthening Palliative Care in Victoria through Health	Victoria	http://arrow.latrobe.edu.au:8080/vital/access/services/Download/latrobe:34550/SOURCE01

Name	Location	Website or resource
Promotion		
Victorian Local Government End of Life Project	Victoria	http://www.mav.asn.au/_data/assets/pdf_file/0018/7632/Victorian-local-government-end-of-life-project-flier-Nov-2016.pdf
Warrnambool Community and District Hospice	Victoria	https://www.warrnamboolhospice.org.au/home
Queensland Compassionate Communities	Queensland	https://palliativecareqld.org.au/qcc/
Margaret River Angels Cancer Support Group	Western Australia	https://www.facebook.com/riverangelsMR/
Silver Chain Palliative Care Service	Western Australia	https://www.silverchain.org.au/wa/health-care/palliative-care/
International examples		
Partnership with Tyrolean Hospice Association	Austria	https://www.researchgate.net/publication/276148546_OA51_Caring_community_in_living_and_dying_-_engaging_communities_through_participatory_research_an_austrian_case_study
Dementia-friendly community pharmacy in Vienna	Austria	https://www.ncbi.nlm.nih.gov/pubmed/25960475
British Columbia Centre for Palliative Care	Canada	http://pallium.ca/infoware/Take%2020%20event%20Speaker%20approved%20online%20version.pdf
Bereavement Support Clinician in Niagara-West, Ontario	Canada	https://uottawa.scholarsportal.info/ottawa/index.php/uojm-jmuo/article/view/1551
Model in Windsor-Essex, Ontario	Canada	http://pallium.ca/infoware/Take%2020%20event%20Speaker%20approved%20online%20version.pdf
Compassionate Frome	United Kingdom	https://www.resurgence.org/magazine/article5050-compassion-is-the-best-medicine.html
Sandwell Compassionate Communities	United Kingdom	http://www.compassionatecommunities.org.uk/files/PDF/CC_Report_Final_July_2013-2.pdf
Compassionate communities in Shropshire	United Kingdom	http://www.compassionatecommunities.org.uk/files/PDF/CC_Report_Final_July_2013-2.pdf
Compassionate communities in Weston	United Kingdom	http://www.compassionatecommunities.org.uk/files/PDF/CC_Report_Final_July_2013-2.pdf
Regional community-based palliative care model in Kerala	India	https://www.ncbi.nlm.nih.gov/pubmed/17482058
Rotorua Community Hospice	New Zealand	http://rotoruahospice.co.nz/

Name	Location	Website or resource
Activities in Limerick	Republic of Ireland	http://www.lenus.ie/hse/bitstream/10147/621066/1/McLoughlin%202013%20Compassion%20communities%20eval%20report.pdf

Toolkits, training materials and information resources

Title and link	Author
A Resource Guide for Community Development of Palliative and End-of-Life Care within Alberta	Alberta Health Services (US)
Briefing Paper: Public Health Approaches to Palliative Care	All Ireland Institute of Hospice and Palliative Care
Building Compassionate Communities	University of Kansas' Community Tool Box / Charter for Compassion
Compassionate Communities Startup Kit	Pallium Canada
Dying Well	Swerissen H and Duckett S, The Grattan Institute
Dying Well Community Charter	The National Council for Palliative Care (UK)
Each Community is Prepared to Help	The National Council for Palliative Care (UK)
Healthy End of Life Project (HELP): A framework for Compassionate Communities	La Trobe University Palliative Care Unit
Public Health Approaches to End of Life Care Toolkit	The National Council for Palliative Care (UK)
Residential Aged Care Palliative Approach Toolkit	CareSearch
Sandwell Compassionate Communities Toolkit	Sandwell Primary Care Trust (UK)
Talking End of Life ...with people with intellectual disability (TEL)	University of Sydney, HammondCare, Flinders University, Unisson Disability, Western Sydney University, CareSearch
The Compassionate City Charter	Allan Kellehear
The Compassionate Workplace	The Groundswell Project
The Ottawa Charter for Health Promotion	World Health Organization

Government resources

Title and link	Author
Compassionate Communities: A Tasmanian Palliative Care Policy Framework 2017 - 2021	Tasmanian Department of Health and Human Services
Conversation Guide: What Matters to Me	Commonwealth Department of Health
National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End-of-Life	Commonwealth Department of Health
Palliative Care and planning for End-of-Life Care	Commonwealth Department of Health
Tasmanian Palliative Care Community Charter	Tasmanian Department of Health and Human Services
Victoria’s end of life and palliative care framework	Victorian Department of Health and Human Services

Websites of key organisations

- [Comcomhub.com and the 8 Groundbreaker communities](#)
- [Compassionate Communities Network – Public Health Palliative Care](#)
- [Compassionate Neighbours in the UK](#)
- [Dying Matters \(UK\)](#)
- [La Trobe University – Palliative Care Unit](#)
- [Pallium Canada](#)
- [Palliative Care Australia](#)
 - [Palliative Care ACT](#)
 - [Palliative Care NSW](#)
 - [Palliative Care Northern Territory \(email\)](#)
 - [Palliative Care Queensland](#)
 - [Palliative Care South Australia](#)
 - [Palliative Care Victoria](#)
 - [Palliative Care Tasmania](#)
 - [Palliative Care WA](#)
- [Public Health Palliative Care International](#)
- [The GroundSwell Project](#)
- [University of Bath Centre for Death & Society](#)
- [Western Sydney University – Developing compassionate community: the caring at end of life research program](#)

Publications

Author, title and link

[Abel K, Kellehear A and Karapliagou A, "Palliative care - the new essentials", *Annals of Palliative Medicine* 7\(Suppl 2\) \(2018\): S3-S14.](#)

[Abel J, "Compassionate communities and end-of-life care", *Clinical Medicine* 18.1-6 \(2018\): 6-8.](#)

[Abel J et al. "Compassionate community networks: supporting home dying", *BMJ Supportive & Palliative Care* 1.2 \(2011\): 129-133.](#)

[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\(3\) \(2015\): e0121101](#)

[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* \(2018\). DOI: 10.1177/0269216318774995.](#)

[Aoun, SM, Rumbold, B, Howting, D, Bolleter, A, Breen, LJ. Bereavement support for family caregivers: The gap between guidelines and practice in palliative care. *PLoS ONE* 12\(10\) \(2017\): e0184750.](#)

[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.](#)

[Grindrod, A and Rumbold, B, 'Healthy End of Life Project \(HELP\): a progress report on implementing community guidance on public health palliative care initiatives in Australia, *Ann Palliat Med*, 7.2 \(2018\):73-83](#)

[Horsfall, D, "Developing compassionate communities in Australia through collective caregiving: a qualitative study exploring network-centred care and the role of the end of life sector", *Ann Palliat Med* \(2018\).](#)

[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.](#)

[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.](#)

[Horsfall D, Yardley A, Leonard R, Noonan K, Rosenberg J, *End of Life at Home: Co-Creating an Ecology of Care* \(2015\), Research Report. Cancer Council of NSW, WSU.](#)

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

[Kellehear A, "The Compassionate City Charter: inviting the cultural and social sectors into end of life care". in Wegleitner K, Heimerl K and Kellehear A eds., *Compassionate communities: case studies from Britain and Europe*. Routledge \(2015\): 76-87.](#)

[Kellehear A, "Public health approaches to palliative care: developments in Australia", *Rikkyo Social Work Review* 23 \(2003\): 27A.](#)

[Leonard, R, Horsfall, D, Rosenberg, J, and Noonan, K, "Identity and the end-of-life story: A role for psychologists." *Australian Psychologist Special Issue: Psychology and End-of-life*. 52 \(5\) \(2017\): 346-354.](#)

[Noonan, K, Horsfall, D, Leonard, R and Rosenberg, JP, "Developing Death Literacy. Progress in Palliative Care" 24 \(2015\), 1:31-35.](#)

[Rosenberg J, "Whose business is dying? Death, the home and palliative care", *Cultural Studies Review* 17.1 \(2011\): 15.](#)

[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.](#)

[Rumbold B, "Public health approaches to palliative care in Australia", in Sallnow, L, Kumar, S and Kellehear, A, *International Perspectives on Public Health and Palliative Care*, Routledge, London and New York \(2012\), 52-58.](#)

[Russell C, "Compassionate Communities and their Role in End-of-Life Care", *University of Ottawa Journal of Medicine* \(2017\).](#)

[Zaman S, Whitelaw, A, Richards, Z., Inbadas, H, and Clark, D, "A moment for compassion: emerging rhetoric's in end-of-life-care" \(2018\), *Medical Humanities*. Epub ahead of print.](#)

References

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

² World Health Organization, 'Ottawa Charter for Health Promotion' (2018): accessed at <http://www.who.int/healthpromotion/conferences/previous/ottawa/en>.

³ Kellehear, A, *Health Promoting Palliative Care*. Melbourne, Oxford University Press (1999).

⁴ 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).

⁵ Palliative Care Australia, Submission PFR329 – Palliative Care Australia (PCA) – Identifying Sectors for Reform Productivity Commission Preliminary Findings (2016), accessed at https://www.pc.gov.au/_data/assets/pdf_file/0005/209480/subpfr329-human-services-identifying-reform.pdf.

⁶ Abel, J, Kellehear, A and Karapliagou, A, see n 1.

⁷ Ibid.

⁸ GroundSwell Project, 'What is a Compassionate Community?' Compassionate Communities Hub (2018) accessed at <https://www.comcomhub.com/learn-more/>

⁹ Sandwell Compassionate Communities, 'What is a Compassionate Community' (2018); accessed at <http://www.compassionatecommunities.org.uk/>.

¹⁰ Abel, J, Kellehear, A and Karapliagou, A, see n 1.

¹¹ Rhatigan, J, "The Compassionate Communities Project", presentation at Living and Dying Well in the Community: The Future of Primary Palliative Care in Ireland (2014).

¹² 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.

¹³ Ibid.

¹⁴ 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.

¹⁵ 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.

¹⁶ Sallnow, L et al, see n 12.

-
- ¹⁷ 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.
- ¹⁸ Downer, K, "It takes a compassionate community: Palliative Care is Everybody's Business", presentation to British Columbia Hospice Palliative Care Association (2016).
- ¹⁹ 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.
- ²⁰ Downer, K, see n 18.
- ²¹ Noonan, K et al, see n 14.
- ²² 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.
- ²³ Sallnow, L et al, see n 12.
- ²⁴ Noonan, K et al, see n 14.
- ²⁵ Rosenberg, JP, Horsfall, D and Leonard, R, see n 57.
- ²⁶ Rhatigan, J, "The Compassionate Communities Project", presentation at Living and Dying Well in the Community: The Future of Primary Palliative Care in Ireland (2014).
- ²⁷ Rosenberg, JP, Horsfall, D and Leonard, R, see n 57.
- ²⁸ Paul, S, see n 15.
- ²⁹ Ibid.
- ³⁰ Ibid.
- ³¹ Rosenberg, JP, Horsfall, D and Leonard, R, see n 19.
- ³² Ibid.
- ³³ Mills, J, Roseberg, JP and McInerney, F, *ibid.*
- ³⁴ 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.
- ³⁵ Ibid.
- ³⁶ Grindrod, A and Rumbold, B, *Public Health Palliative Care Model*, La Trobe University Palliative Care Unit, Yet to be published (2018).
- ³⁷ Rhatigan, J, see n 26.
- ³⁸ Downer, K, see n 18.
- ³⁹ Compassionate Communities Symposium Working Group, see n 17.
- ⁴⁰ Ibid.
- ⁴¹ Ibid.
- ⁴² Rosenberg, JP, Horsfall, D and Leonard, R, see n 19.