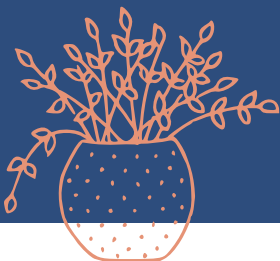




# Building Compassionate Communities in Australia:



**Tools for a community-led  
approach to end-of-life care**



**THE GROUNDSWELL PROJECT**



**Authors:  
Holly Rankin Smith and Niki Read,  
The GroundSwell Project**

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# Acknowledgements

This guidance and toolkit was written and developed in Sydney, the land of the Gadigal people of the Eora nation. It draws upon the experiences of nine different communities around Australia. We acknowledge the traditional custodians of these areas and recognise their elders past, present and emerging.

This resource is the culmination of working in and with communities on the ground throughout Australia. It is influenced and inspired by our colleagues in the United Kingdom, India and New Zealand and our national colleagues at Western Sydney University, La Trobe University and University of the Sunshine Coast.

This resource speaks from the experience of working directly with the following communities in Australia over a two-year period:

- Blue Mountains, NSW
- Sydney's Northern Beaches, NSW
- Bundanoon, NSW
- Newcastle, NSW
- Northern Rivers, NSW
- Dulong and the Sunshine Coast, QLD
- Cradle Coast, TAS
- Warrnambool, VIC
- Bunbury, WA

We thank these communities for their passion, drive and commitment throughout this project, which at times was very challenging. Their perseverance and willingness to share their experiences is a gift to the wider Compassionate Communities movement.

A research report on the work of these nine communities is available to download [here](#) and the recommendations outlined in the report are addressed in this resource.

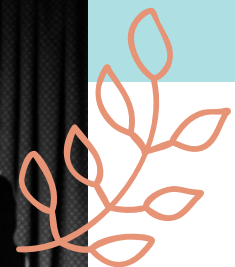
The founding supporter of the National Compassionate Communities Forum initiative was Bupa Health & Care. Research was supported by the Nepean Blue Mountains Primary Health Network.

A grant was provided in 2020 from NSW Ministry of Health to support the implementation of the Toolkit.



‘I think the biggest hope I had was to  
*empower the community*  
to be a part of end-of-life care  
and for people to die better.’

- Compassionate Communities local lead



# Introduction

*'There's no power for change greater than a community discovering what it cares about.'*

*- Margaret Wheatley*

## Welcome.

At the time of writing this guidance and toolkit, there has never been a more urgent time to change the way we age and die in Australia.

In recent years, we have seen interests shift towards improving our experience of ageing and dying. There's been the Royal Commission into Aged Care Quality and Safety. We are seeing the rise of independent and DIY funerals. Voluntary assisted dying is on the agenda of almost every state and territory. And now we're in the midst of a global pandemic that has forced a deeper understanding of social isolation, the vulnerability of the aged care sector and what it means to die and grieve separated from family.

Through all of this, we have also seen and heard stories of communities coming together in love and support. We've seen people rallying to advocate for those more vulnerable and neighbours volunteering to help care for one another. Random acts of care and kindness are being celebrated widely and technology is being utilised in innovative ways to increase connectedness and accessibility.

The time is now to build on the momentum building over the last 10 years and equip communities to take action.

Founded in 2010, The GroundSwell Project works with individuals, organisations and communities to improve how people in Australia die, care and grieve. We run educational workshops, develop innovative programs and advocate for a better end-of-life experience for all.

Since the beginning of 2018, The GroundSwell Project has facilitated a project for nine Australian communities to build Compassionate Communities, communities in which everyday people play a stronger role in the care of people at the end of life. When a community cares about the way people age and die, the Compassionate Communities movement offers a practical way to bring people together to channel that sense of care into action. It offers an opportunity for people from various backgrounds and diverse sectors to share their experiences and then become involved with practical initiatives.

This guidance and toolkit aims to describe the experiences of these communities and the major stages undertaken to build Compassionate Communities in the hopes that others will join the movement. Each community is unique. Some initiatives were started by someone in the health sector, some were started by passionate citizens. Some had access

to funding, others did not. The diversity of the groups has allowed us richer learning.

As it draws on the experience of Australian communities, this resource is specifically relevant to the Australian context, but we hope there will be useful information for people anywhere in the world who want to explore this work.

Often, people are drawn to this work because of a personal experience. Maybe they've been a carer and want to help other carers. Maybe they've seen what it's like to not have a good death or worked in a setting that could provide it. Whatever it is that has brought you here, welcome. We hope that this guidance and toolkit can help create more Compassionate Communities across Australia.

## Useful terms

Throughout this guide, there are many terms used to describe elements of a public health approach to working with communities on end-of-life issues. Many of these terms are used in other settings and there is no one, singular agreed definition for each term. Hopefully, this glossary of useful terms will help you in your work and to clarify the concepts.

**Public health:** The World Health Organization defines public health as 'the art and science of preventing disease, prolonging life and promoting health through the organized efforts of society'. In the context of Compassionate Communities, it is the response of all of the community or society to bettering end-of-life care.

**Palliative care:** Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.<sup>1</sup>

**End-of-life care:** End-of-life care is the last weeks of life in which a patient with a life-limiting illness is rapidly approaching death. The needs of patients and their carers are higher at this time. This phase of palliative care is recognised as one in which increased services and support are essential to ensure that quality, coordinated care from the healthcare team is being delivered. This takes into account not only the terminal phase or when the patient is recognised as imminently dying, but also death and extends to bereavement care.<sup>2</sup>

**Community:** Community is a term that can be used and defined in different ways. For the purpose of this guide, we refer to community as a group of people living in the same area or having a particular characteristic in common.

**Community forum:** A 'community forum' in the context of this guidance is a local event attended by residents and representatives from community and voluntary groups, the health sector, the public sector and local businesses with the purpose of working together to address issues facing the local community, in this case issues around end-of-life care. A key feature of the forum is to value all participants' experiences, create a space for their voices to be heard and use the community's input to shape planning.

**Compassionate Communities:** Compassionate Communities is an approach to social change that aims to promote and integrate social approaches to dying, death and bereavement in the everyday lives of individuals and communities. It raises community awareness of these end-of-life issues and promotes participation in the care and support

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1 World Health Organization. WHO definition of palliative care. Available from: <http://www.who.int/cancer/palliative/definition/en/>.

2 Palliative Care Australia. What is palliative care? Available from: <https://palliativecare.org.au/what-is-palliative-care>



of dying people and their families. Building networks of care, mobilising communities to provide practical and emotional support in skilled and informed ways, and developing resilience are all elements of a compassionate community.<sup>3</sup>

**Death literacy:** Death literacy is defined as a set of knowledge and skills that makes it possible to gain access to understand and act upon end-of-life and death care options. Positioned within a public health framework, death literacy is considered an outcome of people's experiences of and learnings about death and dying.<sup>4</sup> Death literacy can be measured in a population by using the Death Literacy Index. This is discussed more in Stage 3 of this guide.

**Community engagement:** Community engagement is a term used to describe the involvement of community stakeholders in working to address a particular issue or concern. In the context of the end-of-life sector, we look at it through the 'engagement spectrum' developed by Sallnow and Paul to evaluate the level of engagement.<sup>5</sup>

**Community development:** Community development is a holistic approach grounded in principles of empowerment, human rights, inclusion, social justice, self-determination and collective action.<sup>6</sup> Community development supports community members as experts in their own lives and communities, and values community knowledge and experience.

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3 Rosenberg, J. Caresearch Blog: Palliative Perspectives, 'Before I die...' Compassionate Communities in action. Available from: <https://www.caresearch.com.au/caresearch/TabId/3781/ArtMID/6000/ArticleID/71/%E2%80%98Before-I-die%E2%80%A6%E2%80%99-Compassionate-Communities-in-action.aspx>

4 Noonan, K. et al. (2016). Progress in Palliative Care, Developing Death Literacy, Available at: [https://www.researchgate.net/publication/289685169\\_Developing\\_death\\_literacy](https://www.researchgate.net/publication/289685169_Developing_death_literacy)

5 Sallnow, S. and Paul, S. (2015). 'Understanding community engagement in end-of-life care: developing conceptual clarity', *Critical Public Health*, 25:2, pp. 231–238.

6 Kenny, S. (2007). *Developing Communities for the Future* (3rd ed.). South Melbourne: Thompson.



# What are Compassionate Communities?

Compassionate Communities are a key ingredient of public health approaches to palliative care. Compassionate Communities (or ComComs, as some Australians are known to say) are communities in which everyday people play a stronger role in the care of people at the end of life (EOL). Compassionate Communities support and build caring networks using a whole-of-community approach, in turn contributing to wellbeing at the end of life and easing the burden on individuals and the health system.

The movement originated in Australia in the 1990s and was pioneered by Professor Allan Kellehear who remains an active ambassador for this work around the globe. We are now seeing Compassionate Communities emerge as an international model of public health palliative care in action, from the UK and Kerala, India to Canada, Spain, Scotland and more!

The GroundSwell Project are early innovators in the death and dying sector, adopting Compassionate Communities approaches since 2010 in efforts to further the capacity for this movement to grow in Australia. Compassionate Communities are built on what is known as the 95% rule, which acknowledges that a person dying spends about 5% of their time in the last year of life face to face with a medical professional, and that the remainder of the time, 95%, is spent with friends, family, community, online or alone. Compassionate Communities are about building and supporting the quality of that 95% of their time.

With initiatives becoming established in locations around the world, there is a lot to learn from the diverse approaches to the model. Some start at a grassroots community level, working from the bottom up with the community members driving the change. Others start with a top-down model where policy changes in government or health systems lead to changes at the community level. Compassionate Communities become Compassionate Cities when these two approaches come together. This wider impact across sectors sees the bottom-up and top-down approach working together for greater impact and sustainability.

*‘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*

You can find more information and examples of current Compassionate Communities and Cities on the Public Health Palliative Care International website.<sup>7</sup>

## **Why do we need more Compassionate Communities?**

When we think back 200 years ago, before advances in medicine and technology, people aged and died at home. In many cultures, they still do. Family members and neighbours all knew how to support each other and what to expect because it was a familiar, accepted stage of life.

Fast forward to the present day and death has been taken out of the familiar context of the home. It has been medicalised, brought into the health system as a medical problem. As a result, we have lost those experiences that gave us the confidence of knowing what to do, how to help and how to make the most of this precious time at the end of lives. And so people dying and those around them these days have a lack of options, knowledge and decision-making power, and suffer from it.

Compassionate Communities is a way of taking a step back and collectively acknowledging that we each have the capability to step into more active, meaningful, caring and supportive roles when people are dying. The more support we can gather from our communities, the less a burden it is on one or two individuals. Death Literacy research in Australia has revealed that most of us (63%) have at some time sat with someone dying and are comfortable talking about these issues given the right conditions; 27% of Australians avoid talking about death and dying<sup>8</sup>.

*‘It’s recognising that death is a social event with a medical component, not a medical event with a social component.’*

*- Allan Kellehear*

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<sup>7</sup> <http://phpci.info/cities>

<sup>8</sup> Noonan, K, Horsfall, D and Kelly, M (2018). Beyond Taboos? Australians’ capacity to care for each other through death, dying and loss. Research report. The GroundSwell Project. Sydney.



# How we developed Compassionate Communities

The GroundSwell Project identified a gap in the Compassionate Communities movement in Australia. We found there were few examples of initiatives being led from a grassroots community level. We wanted to know how to build Compassionate Communities here at home.

In 2018, with seed funding provided by the health and care company Bupa and the Nepean Blue Mountains Primary Health Network, The GroundSwell Project launched the National Compassionate Communities Forum (NCCF) and a community-based end-of-life care initiative in the Blue Mountains, New South Wales.

The NCCF invited involvement from communities Australia-wide and, through an expression of interest process, involved nine diverse geographical communities across Australia. The NCCF drew heavily on developments in the UK and Europe, in particular the Dying Well Community Charter Pathfinder Project<sup>9</sup>, Health Connections Mendip<sup>10</sup> and Compassionate Inverclyde<sup>11</sup>.

The overall aim of the NCCF was to build upon this international work and explore it within the Australian context. The Caring at End of Life research team at Western Sydney University were contracted to be research partners on the project, with the hope that documenting the progress of these nine communities would reveal knowledge, stories and ideas about how to do Compassionate Communities in Australia and this would enable more communities to embark upon their own Compassionate Communities work.

This figure over the page illustrates the basic model that has been developed through the experiences of the nine communities who were part of the NCCF. It is not an accurate reflection of any one group's experience, but rather represents a number of the similarities and common elements that were experienced across the communities.

This model allows flexibility to shift, adapt and adopt different elements according to the varying values, interests and priorities of each community that implements it. It is also not intended to be 'the only way' to do it, but a way that has seen results and is responsive to the community groups.

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9 Dying Well Community Charter Pathfinder Project Evaluation Report – July 2016.

10 <https://healthconnections mendip.org/>

11 <https://ardgowanhospice.org.uk/how-we-can-help/compassionate-inverclyde/>

## Community-led approach to developing a Compassionate Community



# A public health and community development approach

*‘A public health approach to end of life care, views the community as an equal partner in the long and complex task of providing quality healthcare at the end of life.’<sup>12</sup>*

The model is based in both a public health approach and a community development approach.

The core elements of a community development approach to end of life can be described as follows, drawing on the Ottawa charter for health promotion<sup>13</sup>, the principles of a new public health approach to end of life and palliative care<sup>14</sup> and community development practices:

- Building capacity and death literacy through education and shared experiences
- Value and focus is on existing community strengths and assets
- Community recognised as the experts on their own life and valued as key stakeholders not just participants
- Community identifies needs and is empowered to lead the change
- There is a focus on equity and inclusion with a broad understanding of health and wellbeing
- Sustainability is a core element achieved through partnerships and shared leadership
- Having a whole-of-community approach, recognising that palliative care and health services cannot do this alone
- Thinking beyond individuals to include social and community networks

There are a lot of different ways to implement community development and the definition has changed over time and in different contexts. For the purposes of this guidance, think of community development as a set of strategies and ideas that act to empower community members to make active choices and decisions about what is best for them.

It is not about deciding or assuming what would be good for the community and then developing strategies to make that happen. It is essential to listen to the community first and foremost. Someone working with a community development approach would view their role as assisting and enabling community members to make changes in their own lives, not implementing changes that have been decided for them. It is also essential to ensure representation from as much of the community as possible, with ongoing consideration for whose voice is missing.

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12 See <https://phpci.info/>

13 Ottawa Charter for Health Promotion, 1987 World Health Organisation

14 Sallnow, L., Richardson, H., Murray, S.A. and Kellehear, A. (2016). ‘The impact of a new public health approach to end-of-life care: A systematic review.’ *Palliative medicine* 30.3, pp. 200–211.



## RESOURCES FOR FURTHER READING:

- Ottawa Charter (WHO 1986)
- Public Health Palliative Care International
- The Compassionate City Charter - PHPCI
- Podcast: How to Build Community with Cormac Russell
- Asset Based Community Development – how to get started
- Asset Based Community Development by Community Door

## Identifying barriers and strategies to overcome them

As part of the project to build Compassionate Communities in Australia, Western Sydney University researched the groups involved to identify barriers to success and strategies to overcome them. The groups in the nine communities in Australia were called 'Groundbreaker' groups. The research process captured the progress of the Groundbreaker groups through focus groups across an 18-month period. The report *Researching Compassionate Communities in Australia: A short term, longitudinal study* can be [accessed here](#) but here we present a summary of the findings of the project.<sup>15</sup>

### Resistance and struggle

**Questioning legitimacy.** It was a common experience for people leading Compassionate Communities initiatives to question their ability to undertake leadership roles. This was equally strong for people coming from a health background or community organisation. This could partly be due to the emergent nature of the movement with few examples to draw from within an Australian context and the community development model preventing too many predetermined strategies. People in/from a health setting, most of whom had no previous experience in community development, felt a tension between themselves as members of their community and their professional selves in a health setting. This theme became less apparent over time as participants became familiar with, and confident in, their work and as actions within their communities began taking place.

**Coming face to face with gatekeepers.** Gatekeeping is a well-recognised strategy used by those with power and control to maintain the status quo. All participants came up against gatekeepers over the course of this project which further impacted the questioning of legitimacy. Some of the gatekeeping strategies that were experienced included obstruction, misinformation, take-over attempts, trivialising, and being disciplined to stay in their place. The people who engaged in gatekeeping behaviours represented a diverse cross-section of this field, including but not limited to international and local academics, leading practitioners, medical practitioners, health leaders and local community leaders. This theme also diminished over time.

**Compassionate Communities as women's work?** Gender was discussed across the time of the project. There were only a few male participants in community meetings and the overall Compassionate Community work. The issue of gender is an ongoing conundrum for the Compassionate Communities movement and many of the participating communities discussed ways to further include and activate men in the community. The

<sup>15</sup> Horsfall, D. et al. (2020) *Researching Compassionate Communities in Australia: A short term, longitudinal study*. Sydney: The GroundSwell Project.

movement risks exploiting unpaid labour and reinscribing the notion that developing Compassionate Communities and providing *on the ground* caring is women's business and work.

**Exhausting and exhaustive expectations.** The nature of community development work was in itself overwhelming. Multiple expectations from multiple stakeholders, with a limited understanding of community development, or a workplace culture which reflected the dominant health/service provider ethos, added pressure and distress. In particular, the type and nature of evidence being demanded of the participants was problematic. Participants focused on relationship building as the first stage in developing community capacity. However, the time this takes often went unrecognised or unacknowledged. Stakeholders needed answers, roadmaps, toolkits, impact statements and measures of success in a language they understood, often devoid of the humanness and complexity which is the very lifeblood of Compassionate Communities.

## What does it take to do this work? Strategies for success

**A clear understanding of community development to drive strategies and actions.** Most of our participants had a solid understanding of community development and were committed to developing Compassionate Communities using the original community development approach, which is about relationship building and a global vision of self-determination and community-centric values. Community needs drove the strategies of participants as they built support from the ground up. Critical to success was the generation and allocation of formal resources and increasing bonding and bridging ties between community members. They tirelessly built alliances and relationships and stood by that old grassroots model with the attitude that if it doesn't work, rethink it, learn from it and try again. They made themselves public, wrote submissions, applied for grants and raised funds. They persevered. This was a strength of the work.

**Deliberate communications: Using language, being strategic.** The Groundbreakers learnt to speak in different ways according to who their audience was. This enabled connections with everyday folk in their communities *and* service providers, policymakers, local politicians and medical professionals.

**Collective leadership: Moving from the 'I' to the 'we'.** Participants struggled to share leadership with those in their communities who appeared to resist taking responsibility or doing the work that needed to be done. Nevertheless, they persisted with helping their communities to collectivise the work and encouraged them to become self-reliant. This theme became less apparent over the life of the project as the communities moved into the action phase of their work and as leadership became a set of actions rather than a role or position.

**Reflective and collegial spaces for people working in precarious places.** Developing collegial spaces of support, encouragement and knowledge sharing that fostered critical consciousness and solidarity-building was fundamental to supporting participants. Being part of a national forum with a respected not-for-profit organisation was also important. They valued the ability to call upon expertise and support from people who had clear understandings of community development and Compassionate Communities. Being part of an actively supported network meant that they were conscious of being part of something bigger, a movement. In 2021, The GroundSwell Project will pilot a community of practice, a collegial forum of support and discovery for different stakeholders looking to use this guidance and toolkit to start Compassionate Communities initiatives.

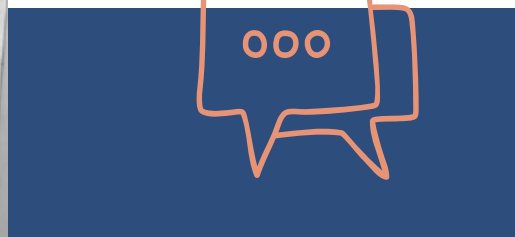
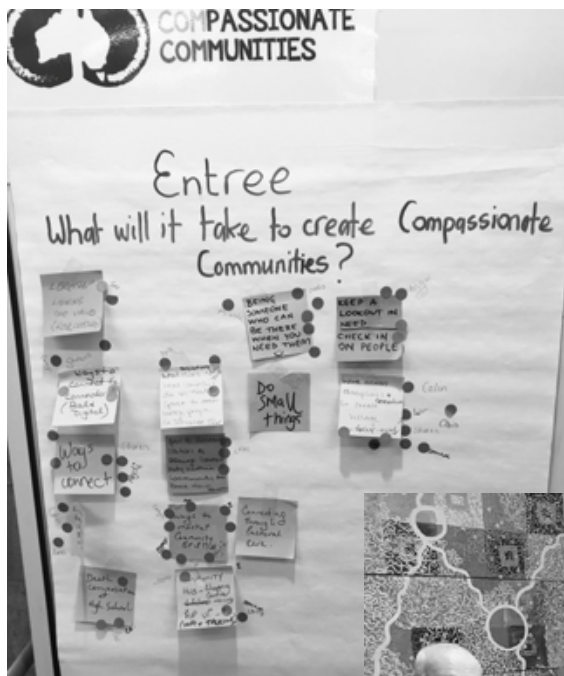
**Our voices, our stories: Sharing stories of success.** There was evidence of tangible changes in relationships between formal and informal services and networks. There was also evidence of changes in the way communities came together to care for each other

in times of need. Participants reported that these changes could be sustainable as they were becoming woven into the fabric of community life. Despite a relatively short period of time and little or no resourcing, in the final focus group participants enthusiastically recounted the ripple effects of their work permeating their communities as communities became self-organising and self-determined.

## RESOURCES FOR FURTHER READING

Read national research on building Compassionate Communities as well as stories of other community groups around the world and the challenges and successes that they have experienced:

- **Researching Compassionate Communities in Australia**
- **Beyond Taboos**
- **Developing Death Literacy**
- **Co-creating an ecology of care**
- **Public Health Approaches to End of Life Care Toolkit**
- **Dying Well Community Charter Pathfinder Project evaluation**
- **Compassionate Inverclyde Evaluation**
- **Bringing Our Dying Home**
- **Nous Report, Australian Government commissioned feasibility study**



# Overview

‘We just had a lady who died at home last week. She was a volunteer herself for over 20 years at the hospital and in the last years of her life has been quite unwell and in the last 7 or so months we’ve [the local volunteer-run hospice] been involved. She had support from palliative care volunteers. She had support from our volunteers. She had friends who were regularly visiting and caring for her. Her family were caring for her at home and she loved sitting in her lounge room, looking out at her beautiful garden or lying in bed and looking out at her beautiful garden. And she really wanted to die at home and even though she lived alone, she got that wish by all these people being involved. It’s a classic compassionate community in end of life at its best.’

Compassionate Community lead, VIC



This guidance and toolkit is an evidence-based approach, a reflection of what we have seen and experienced by working in communities. It might be a good starting point for you, or it might offer some insight on community approaches to inform an element of your existing work. Our hope is that this resource offers some insight into what we've learnt about where Compassionate Communities are at in Australia now so that more people and more communities can feel inspired to approach this work in a way that best suits them.

Just as there is no one 'type' of community, there is also not just one specific approach to Compassionate Communities that will work everywhere. End-of-life support is complex. The Compassionate Communities approach is responsive to the strengths, needs and values of each community setting which allows it to embrace the complexity and diversity of all involved.

This guidance and toolkit encourages you to create an approach that works to the strengths and priorities of your community, putting the community in the driver's seat. So, how the approach develops may look and work differently in each community setting.

You are invited to use this resource in the best way that suits you. Use it as a starting point and weave in your own ideas. Adapt it to your own networks and community. Maybe it will assist you in developing a project plan or the basis for a grant proposal. It is yours to make what you will of it.

Now that we've reviewed the concept of Compassionate Communities and described our work in the area, this next section reviews the three major stages in developing Compassionate Communities and creating actions and initiatives to build this development.

**Stage 1** is about mobilising the community and finding allies for your work.

**Stage 2** is planning for and implementing a community forum to allow those interested to share their priorities and vision, as well as identify the resources available in the community to move from meetings to action.

**Stage 3** is what happens after the community forum. Can you form an action group? Will there be follow-up meetings? What actions and initiatives can now be embarked upon to further develop your Compassionate Community?

And remember: You're not on your own. A Compassionate Community will need many people working together to create it, and we at The GroundSwell Project are always happy to hear from you, act as a resource and provide the support we can to you.



# Stage 1: Community mobilisation

The crucial first stage of creating a Compassionate Community is to find your allies. To do this, it's important to hear from people about what matters to them! You might already have a start on this dialogue if end of life is part of your work or you have networks that are connected with end-of-life work. If so, fantastic. If not, that's okay. The likelihood is that there are more people as passionate and keen to see change as you. It's about seeking out your allies.

There are plenty of ways to work out who might be interested in this kind of work, which we'll explore below.

Here are a few questions to consider both for yourself and for potential allies:

- Why are you interested in Compassionate Communities? What draws you into this work?
- Have you been the carer for someone?
- Have you had an experience with the health system that could benefit from more community involvement?

Finding your allies and gauging the interest of the community is a really important first element that comes back to the core of community development – a project is more likely to fail if you approach it as ‘doing it for’ or ‘doing it to’ the community. So first you need to gauge whether there is interest from the community to see changes in how we approach end of life and to identify what specific issues or concerns they really care about.

We have found that once there’s a safe space to talk about how we deal with death and dying, people often have a lot of experiences and are keen to share! Once you have some like-minded people engaged, stretch your reach further. Compassionate Communities is a whole-of-community approach to end-of-life, so how can you engage with those who are harder to reach in your local area?

One place to start might be your local council, Aboriginal Land Council (or state equivalent) and neighbourhood centre. There might be contact points for different cultural groups or initiatives already in place that help reach different demographic groups. Another tactic might be to enlist the help of others to get the word out. As you connect with people in your own network about Compassionate Communities, ask them who they might know who would be interested in being involved: maybe a social group that they’re a part of or connections through a family member. Great allies can be found through unlikely sources.

## Be one step ahead – Have the community gathering at the front of your mind in all conversations

While Stage One is finding your allies, Stage Two is bringing them together at a community gathering. So, as you meet and connect with people, have the potential gathering in mind and talk to people about it. Ask them if they would attend a gathering to explore more ideas as a community. This might help you shape how and what that meeting might look like. And always get contact information of the people you meet so you can invite them to the gathering and future opportunities to connect.

The goal is to rally interest and get people to that gathering where the wealth of knowledge of the community will be valued and captured to help shape the way forward.



*‘Thank you for sharing your experience with me, I think it’s really important that we do something about this. Would you be willing to come and share your story at a community forum?’*

## Follow leads and extend from your own networks

If someone told you about a fantastic bereavement group that supported them, find that group! Start thinking about the different places, organisations and services that might be relevant to people and families in terms of ageing and end of life. Also consider people who work within the end-of-life sector who might want to see change. Champions working within the system can really help to create bigger change and drive it in areas we might not have access to!

## Questions for reflection

What already exists in our community to support people to have a better end-of-life experience?

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Why am I passionate about this? How can my experience help me find allies?

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What local groups and services could I approach about this work?

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# Stage 2: Community gathering

During the National Compassionate Communities Forum, the Groundbreaker communities were encouraged to host a community forum as a gathering that would bring people together. The format was interpreted differently by each community group but the overall aim – to bring different sectors of the community together to share experiences and work out direction – was common across all.

‘People were very curious, [they were] there to find out more. The way it was intentionally structured was to make it more about getting community thoughts and ideas rather than purely being a top-down instructional session so I think the fact that there was that hands-on workshop element to it where people had to brainstorm, think up ideas, worked really well. People didn’t feel like they were just there to be talked to or even be humoured into thinking they were being consulted somehow. No, it was a genuine consultation. People went in there with curiosity and left feeling like they’d made a contribution.’

- Community Lead, NSW



# Plan the gathering

## A digital gathering

At the time of writing, COVID-19 is still in full force with many parts of Australia and the world not able to gather in the way that the Groundbreaker communities were able to. Yet the purpose and need for these initiatives is greater than ever, especially at times like this. If you are unable to gather people together physically, there are still options for how to keep building a Compassionate Community.

Here are some ideas:

- Check with your local health authorities regularly to ensure you are adhering to restrictions.
- If restrictions are in place, consider scheduling a couple of smaller get-togethers and then combine the outcomes of the discussions.
- There are many digital tools available that can help facilitate discussion such as Zoom<sup>16</sup> which has become widely used during the COVID-19 pandemic. If digital technology is not your cup of tea, reach out to your community as a way of inviting people to share their ideas and views. Someone might have some great ideas about how to capture community thoughts.

One of the Groundbreaker communities wanted to reach more people in the community after their forum gathering. They decided to do a letterbox drop and ask the community what their priorities were and also whether they needed any support or were able to offer any. This kind of idea could also work well as a first point of contact if physical gatherings are not an option.

## An in-person gathering

If gatherings can take place, let's discuss the planning. Planning the forum is a great opportunity to engage people and organisations.

Some questions to consider:

- Who might be able to help you with finding a venue for the forum?
- Could you approach your local bakery, grocer or Country Women's Association (CWA) to assist with catering for the event?
- Does your local council have any events coming up that you could link with to promote the forum?

Exploring all of these avenues becomes an opportunity to connect and involve people and groups in the forum – and hopefully with the wider project.

## CASE STUDY: Support from a local council

One of the Groundbreaker groups was planning their forum with very little budget. When looking for a venue they approached the local council and were able to explain the aims of the event, some of the partnerships involved and the potential impact it could have on the local community. The local council sponsored the event by way of providing an excellent venue in a prominent part of town and assisted with some marketing collateral. This served the group not only by having somewhere to host the forum, but by having the opportunity to discuss the aims and objectives of the forum with the council, making them aware of the wider project. This opened up a dialogue with the council who were able to see the benefits of the work and offer some in-kind support.

## Dying to Know Day as an engagement tool

Dying to Know Day is an annual campaign that promotes community-run events that encourage conversation and action around the end of life. You can find more information at: <https://www.thegroundswellproject.com/dying-to-know-day>

Using the growing response to this campaign can be a great way to kick off some Compassionate Communities conversations in your area. It can be easier to gather people together over a shared purpose and offers a great way to gauge community appetite for these conversations.

Aligning your gathering with an existing event can also offer a sense of legitimacy to more formal organisations and services who might align with the aims of the campaign and be interested in partnering with you.

## Logistics

Now that you've been out talking and listening and you know that a good cross-section of the community are interested, it's time to plan how the event will run.

**Date and time:** Throughout the National Compassionate Communities Forum, there were community forums hosted during both the day and at night as well as on weekdays and weekends. It hasn't been shown to make a huge difference to numbers either way so put the feelers out as to what will work best for your community or when your venue is available. Have you set the date with enough time to plan it properly? Are the key people involved able to attend? Are there any competing events that would prevent people from coming? For your target audience, what kind of considerations do you need to make before choosing the date and time to ensure that the most people possible are available?

**Time:** From our experience, the forums have generally run for about 3 hours. This gives a good balance of speakers and discussion time. It is better to have more time than needed than to risk people feeling they didn't get an opportunity to contribute.

**Promote:** Hopefully through your experience of finding your allies and talking with community members you have been building a contact list. This will form your invitation list for your forum event. The people you've spoken to, venues you have visit, services you have enquired about, all of these contact points are now avenues to promote the forum. It could be a simple email with the details that people can forward on or it might be a physical poster or flyer you distribute.

**Attendance:** Attendance at the forums throughout the NCCF ranged from 25 people to 150 depending on the size of the community. Don't worry too much about numbers. Five people who turn up and are really passionate can garner more effective results than 200 people showing up and not staying engaged. What's important is that the invitation has gone out widely enough to reach a diverse mix of the community.

**Format:** The structure of the event is up to you and what you feel might work well. We have seen a fairly diverse range from a morning of sharing stories with a few guest speakers, to a more structured evening event in the style of a World Cafe with themes and discussion points, and to a mini festival with a range of activities and ways to engage. Keep in mind that the purpose of the forum is to capture the community's opinions around having a good end-of-life experience and to look at what we can do to improve it – together. Let that guide the structure.

## Top tips

Here's what we've learnt from the Groundbreakers along the way and can share with you as our top tips for running the Community Forum.



*Fun activity at the first community forum of the NCCF in Dee Why, NSW.*

## Expectations

It's natural to want the first gathering to be really special, maybe at a nice venue with good catering. But keep in mind that this is the first contact people will have with the project and it may set up expectations of what will be provided on an ongoing basis. If the forum has great catering, people might assume there will be catering provided next time rather than offering to contribute in some way. Will people expect every meeting to be at the RSL function room or do you want people to take ownership and offer to host meetings too? Consider the values you want to foster in this project and weave them in from Day 1.

## Create an interactive space

It's important that the forum be held in an interactive and shared space with room for different voices to be heard and where everyone's opinions and experiences are valued contributions. By bringing the wider community in from the beginning, we foster a sense

of investment and shared value. It also ensures that the outputs of the project are really relevant to the community and aligned with the values, skills and interests in the room. This is key to the sustainability of the work.

## Plan a good balance of speakers and discussion time

Inviting a couple of speakers is a great way to get people inspired and to spark discussion. The speakers don't have to be famous or from the health sector. Think about community members who have had a valuable or positive end-of-life experience. Consider hearing from a First Nations perspective, maybe someone who has helped care for the dying, a death doula or a respected GP who has helped people die in their own home. Although speakers are a good way to help spark discussion, it's important that there is a good balance of listening to speakers and space for discussion and sharing. It's a good idea to have an experienced facilitator who can help guide the discussion and to capture insights.

## Capture community insights

Think about how best to capture the insights that are shared on the day. These insights will help you to start shaping what steps to take next.

- Do you want people sitting around tables with butchers paper and coloured pens?
- Do you want someone to be a scribe or to record the session digitally?
- Will people write their thoughts and ideas collectively on a whiteboard? Or use Post-it Notes?

One of the Groundbreaker groups had conversation cards to spark discussion on each table and were asked to reflect on some of the questions in smaller groups. When the groups all came back together, the facilitator captured different themes from the discussion.

Another group didn't use conversation cards but did structure the discussions by providing specific questions at each table for the groups to answer together and discuss.

Two of the Groundbreaker groups used a World Cafe format which encouraged groups to get up and move around to discuss different topics. Whatever you decide to do, think creatively and try to determine what will encourage maximum community interaction.

## Call to action and follow-up meeting

Using the Death Literacy Index is a great way to identify and unpack community priorities, we discuss the index further in the 'tools and initiatives' section on page 38 .

A strong call to action to stay involved and a follow-up meeting already scheduled will add momentum to the movement. The call to action might be encouraging people to sign up to part of the leadership group or a commitment to share details about the next gathering.

Encouraging people to RSVP is a good way to gather contact details to add to a database and do follow-up and the physical 'signing' up to something can be empowering and symbolic. And they can share that date with their contacts while it's fresh in their minds. Ideally, you will have a follow-up meeting date locked in so people can put it in their diaries then and there. Delegating some of the responsibilities for the next meeting is a good way to share the leadership and get people to the next event.

# Example running order

## 8:30am: Arrival and Sign In

- Have someone whose sole purpose for the day is to welcome people. It can make a big difference to people's comfort and willingness to share if they feel a connection to someone when they arrive.
- Have a sign-in sheet – this makes it easy to track attendance numbers and is essential in terms of following up easily.
- A tea and coffee station is a good idea that provides somewhere for people to mingle

## 9am: Welcome

- Welcome people and introduce yourself
- Welcome to Country by a local First Nations elder or an Acknowledgement of Country if that is not possible
- Why are we here? Share the intention for the forum and reiterate how valuable everyone's experience is. Be sure to extend the invitation to be part of the broader event too.

## 9:20am: Background to Compassionate Communities

- Offer a brief background to Compassionate Communities
- Screening of the Allan Kellehear video that launched the Western Australia forum event.
- Share the Compassionate Cities Charter to give context or just share the last paragraph as a guiding statement

## 9:40am: Local Stories

- Guest speakers to share reflections of end of life in our local area
- Local GP who has helped people to die in their own home
- Doula who has worked with many people at end of life and their bereaved families
- Local person who has been a carer
- Allow for some people in the room to share their story if they want to

## 10am: Morning Tea and Discussion

- Tables are set out with butchers paper and colour markers and should have one person as 'captain' of that table, ensuring thoughts are effectively recorded on the paper.
- Each table is encouraged to start with the opening question: What really matters to us as a community when it comes to ageing and dying well?
- Next, it might work to move into discussion about some of the different elements of ageing and dying. Each table could be given a specific topic or each table could address multiple topics. Some ideas of topics for discussion are:
  - Grief and Bereavement
  - Death and Dying
  - Social Isolation
  - Aged Care

- Each topic could have some guiding questions, such as:
  - **Question 1: What do we have already that helps address this issue?** *This question helps to map what end-of-life assets already exist in the community and highlights community strengths.*
  - **Question 2: What is missing in our area when we think about this issue?** *This question helps identify gaps that are important to the community.*
  - **Question 3: What can we do to address this?** *This question helps to capture what ideas people have and can inform the next steps in terms of choosing an initiative to prioritise. Encourage people to be specific with what skills or experience they can offer.*
- Invite people to chat and discuss for 15 minutes or so before moving to a different table or topic. Allow for about three topic changes so people can share their insights on different areas.

## 11am: Collective Discussion

- Bring the attention of the groups back together
- Ask each table 'captain' to share some of the insights from that group and allow others to add or comment as they go
- If you have someone acting as scribe, make sure they capture these collective discussions as it can help inform your direction after the forum.

## 11:45pm: Wrap Up and Call to Action

- Share some positive reflections on what has been shared.
- Be responsive to the discussion. If there weren't many assets discovered, focus on the vast experience of the group or the passion in the room.



- 'I'm amazed to learn there are so many different groups and resources that I didn't know we had in this area!'
- 'There's a lot of wisdom in the room here. I have already learnt so much just from hearing some of your experiences. I really appreciate you being so willing to share.'
- 'It's really inspiring to hear all these great ideas for ways we could improve the end-of-life experience here.'



## What's Next?

- Have the next meeting date locked in, even if the other details aren't finalised. Encourage people to write it down or have flyers with the information prepared.
- Talk about the need for people to help drive this – in lots of different ways with different levels of commitment. Invite people to be part of the action group to use their skills to help determine next steps.
- Remind people to make sure they've signed up to the contact list so they can stay informed and their voices remain heard.
- Document the discussion from the gathering – this will become your guide as to what's next or will be a valuable thing to hand on to someone else to lead.

# Common priority areas from the NCCF

Throughout the NCCF there were nine different community gatherings. Each one kickstarted the momentum in the community. In observing each of these we discovered common issues of concern raised by community members at the community forums. These concerns became priority areas of action and offered a good starting point for what the next steps might be.

Here are some examples of the priority areas and some of the ways the communities worked to address them:



**Community members don't know where or how to access local end-of-life services**

- Develop a community directory of local end-of-life groups and services
- Connect with your Primary Health Network and work together on some community information evenings
- Partner with your local Neighbourhood Centre to discuss information flyers



- Start a regular cafe meet-up such as a bereavement support cafe or a **Death Cafe**.
- Start an art-making group as a place to connect and create
- Promote gatherings through local palliative care services and welcome referrals
- Share the leadership of the group; take it in turns to organise and promote

**The lack of regular, safe opportunities to connect with others to support and share experiences around dying, caring and grieving**



**The need for a practical way for community members to help each other**

- Set up a digital space to offer help and respond to people's needs. This could be as simple as a Facebook group or could use **Gather My Crew** as a network organising platform.
- Run a **Community Connector training**
- A community volunteer roster partnering with a local organisation or facility in need



- Run end-of-life workshops and seminars such as the *Ten things to know before you go* end-of-life workshop
- Share end-of-life resources such as the **Death Literacy Library**
- Encourage volunteering at a local hospice or palliative care service – learning by doing.



**How to increase death literacy – opportunities to learn more, educational resources to better prepare community members**

### **More equitable access to funerals**

- Develop a greater understanding of your rights when it comes to caring for a loved one after they die – look up legislation for your state
- Seek out people in the community who have had the experience of organising a funeral
- Be inspired by **Natural Grace Funerals**. If there's enough interest and support, explore starting a community-led funeral initiative such as a **Coffin Club** or **Tender Funerals**.

## **Back to the drawing board**

Valuing roadblocks along the way is hard but it's important. Many of the Groundbreaker community groups started activities or pursued opportunities that didn't lead to anything significant or didn't work out in the way they had hoped or anticipated. This can be frustrating and discouraging but it is important to remember that it is completely normal. If something doesn't take off, it is an opportunity to get feedback, to discuss ways to build on the idea or another idea entirely. It's not a sign to give up, but a chance to change direction. And remember, we never know the future impact of the conversations and planning that go into organising something. Talking about end-of-life issues more broadly in the community is significant in and of itself and can build momentum for future opportunities.

## Questions for reflection

The key things that stand out for me in this section are ...

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What are some of the barriers I can see in running an event?

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How could these be addressed or how could I reframe the gathering (e.g. letterbox drop or online discussion)?

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What are some of the local stories we could share?

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*Next page: Examples of NCCF community flyers promoting their community gatherings.*

# THE COMCOM CAFE

• COMPASSIONATE DINING •

## ENTREE

Served on a bed of 'focus upon what matters' and 'contribution of thinking' with a perfect blend of mind and heart

## WHAT WILL IT TAKE TO CREATE COMPASSIONATE COMMUNITIES?

## MAIN

Served with a side of 'listening to understand' and 'listening for deeper insights and questions' with a drizzling of sauce to link and connect ideas

## WHAT UNIQUE CONTRIBUTION CAN WE EACH MAKE?

## DESSERT

Served with a warm, rich syrup of fun and chards of 'play, doodle and draw'

## WHAT NEEDS OUR IMMEDIATE ATTENTION?

\*A city is not merely a place to work and access services but equally a place to enjoy time in the safety and protection of each other's company, in schools, workplaces, worship and recreation, in cultural forums and social networks, in parks and public spaces. In fact, even to the extent of our influence, even to the extent of our lives.



# MINI DEATH FEST

Free event

a festival for life, death and how we can support each other at end of life

WEDNESDAY  
AUG 8

2-6PM

BUNBURY REGIONAL ENTERTAINMENT CENTRE

## Bundanoon - A Compassionate Community Meeting Invitation

Bundanoon has been selected to be part of The Groundswell Project's Compassionate Communities Forums. Let's chat about what this means for Bundanoon!

Date: Saturday 30 June 2018  
Time: 3pm to 6pm  
Location: Soldiers Memorial Hall, Bundanoon  
Cost: Free  
RSVP: comcombundanoon@questforlife.com.au or via Eventbrite

The Compassionate Community Movement is changing how we talk about and deal with illness, death, dying and end of life, but being a part of a Compassionate Community can help. The only way to have a Compassionate Community is to build it together. Contribute to what we can do better and differently to make our communities more compassionate.

A global movement focused on building compassionate communities around death and dying in our region. Find out how compassionate communities can help.

Share your experiences of illness, death and dying. Compassionate Community Planning sessions and a few laughs.



9.30AM  
THURSDAY 12 APRIL 2018

DEE WHY RSL, 932 PITWATER ROAD, DEE WHY

The Compassionate Community Movement is changing the way we talk about and deal with death, dying and grief. In general, our fear of death stops us from accepting and planning for a good end of life. This fear also stops us from living a great life. How well we do dying depends on how compassionate a community is towards the person dying and those who matter to them.

Come along and contribute to what we can do better and differently to make the Northern Beaches community one of the most compassionate communities in the world.

You can expect to:

- Contribute to a global movement focussed on building compassionate communities;
- Learn about death and dying in our region;
- Discover how compassionate communities can make a difference to their families;
- Share your experiences of death, dying, grief and bereavement.

## INVITATION COMMUNITY FORUM

### Creating Compassionate Communities

Wednesday 31 October 2018  
Maroochy Bushland Botanic Gardens  
Arts & Ecology Centre  
Register at 8.30 am  
Starts at 9.00 am to 12.30 pm

FREE

Interesting guest speakers  
World Café Discussion  
Harvesting Ideas & action

Let's open up conversations about death and dying in our region. Compassionate Communities approach to end of life care where caring for another at times of need, loss and grief becomes the task and responsibility of everyone.

## BLUE MOUNTAINS OUR COMPASSIONATE CITY

Community meeting about better care for all at end of life. The best community is one we build together - the way we want it.

- Have you cared for someone at end of life?
- Would you like to be a part of a world-wide social movement to increase well-being for people at end of life?
- Want to be a part of building a community road map to an integrated compassionate community in the Blue Mountains?

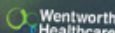
ALL WELCOME

RSVP cut + paste the link below  
<https://www.eventbrite.com.au/er/blue-mountains-comcom-tickets-48081625436>

8th August  
3-5.30 pm  
Junction 142  
142 Katoomba St  
Katoomba

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.

Alan Kellehear



The service has been made possible through funding provided by the Australian Government under the PHN Program.



## Compassionate Communities Forum

Hosted by the Northern NSW Local Health District & North Coast Primary Health Network

One thing's for sure - everyone dies.

Let's open up conversations about death and dying and talk about fostering more compassion within our communities.

Come along to this free community forum and join health professionals, community members and friends to talk about this sometimes awkward subject.

- Hear from others about their experiences with dying and grief
- Contribute your stories and ideas
- Help start building our Northern Rivers Compassionate Communities
- Tea, coffee and light snacks provided

Get involved - register at:

Monday 2nd July 2018  
5.00-8.00pm

Ballina RSL, 1 Grant St  
THE GROUNDSWELL PROJECT



# Stage 3: Where to next?

Where to next? This will largely be informed by the needs and priorities identified by your community and what kind of response you've got from your call to action to stay involved. The aim for the next stage is to take action on one or more of the priority areas of concern to work out how best to approach these and then to apply an action learning model (which is described below).

The following outlines some key next steps for this stage and some essential elements to be aware of as you move forward.

## Follow-up meeting

At your forum, you should have made sure you collected people's contact information and also made sure they knew the date of the next meeting. This follow-up meeting will be significant in working out next steps. The likelihood is that people who attend the follow-up are committed to being involved on an ongoing basis.

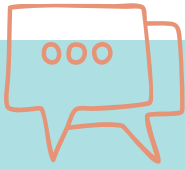
You should formalise this in some way. You can give the group a name, like action group, committee or steering group, but make sure this doesn't become exclusive. Ensure the door is always open for other people to feel they can join in and give their input. Agree on how often you will meet and share some of the facilitation and logistic roles.

**Remember, the greater the sense of shared ownership, the greater likelihood of ongoing sustainability.**

At your forum, you have captured some insights from those who attended. Use these insights to help inform the next steps at the follow-up meeting.

Some questions to consider are:

- What issues sparked the most discussion or were raised more than once? This gives you a good sense of what the community would continue to support.
- Does your local council already do something to address the issues raised? Could you focus on helping to further amplify something that already exists rather than starting something from scratch?
- If not, what kind of support is needed to act on this issue? Who is in the community that you could draw on for support in taking action?

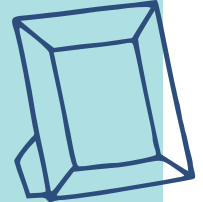


‘It’s about building the networks between the people that are in need and the people that can help.’

- Community Lead, NSW

‘Being aware of everything that’s happening in the area and not try and do what someone has already done – but expand on what people are doing and join with them rather than doing something different and becoming siloed.’

Northern NSW lead

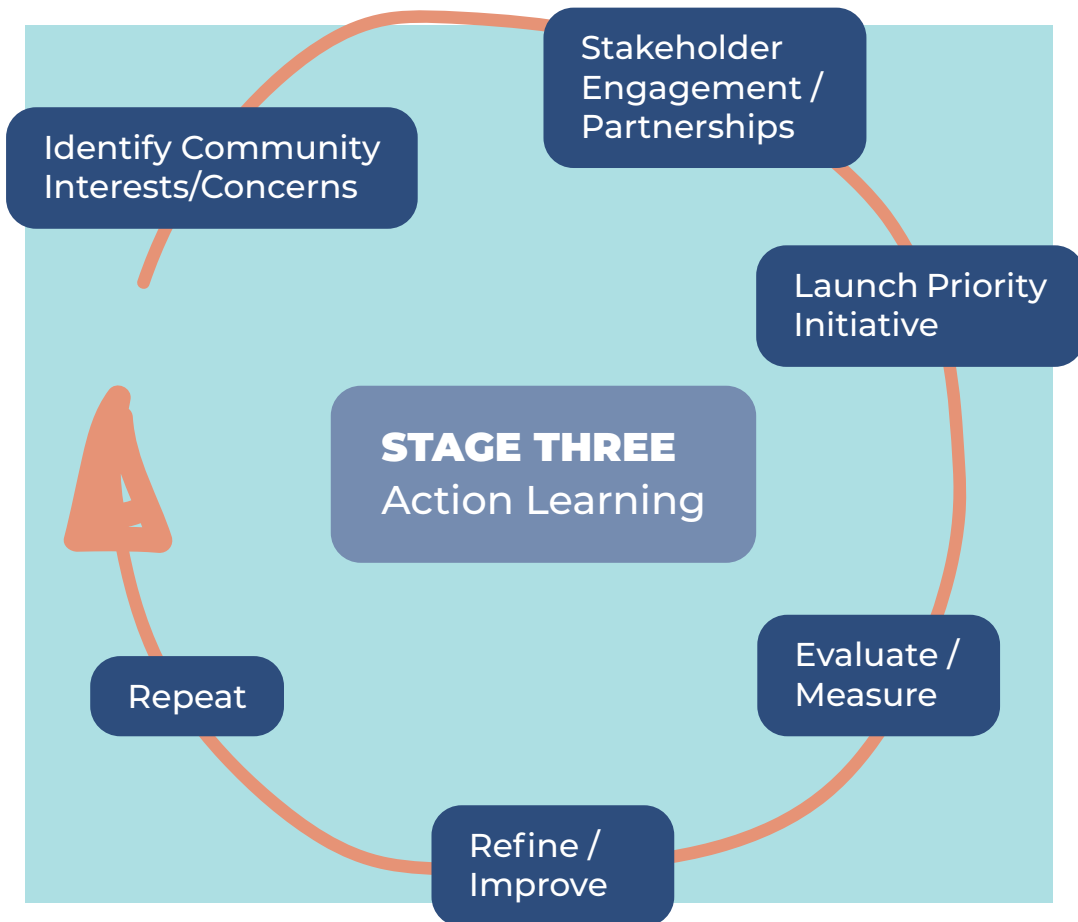


‘People felt in the dark. That’s what led to our program of workshops here. For me it was so good to see that people wanted to talk and needed to talk. In each of the workshops we’ve had so far, we’ve tried to make sure there’s time for as many people as possible to have time to talk or ask questions.’

- Southern Highlands NSW Lead



# Action learning model



Action learning is a common method in community development, social change and social entrepreneurship. It involves experiential learning where decisions are made, action is taken and reflection on the action is key in determining changes. It is a useful model in the Compassionate Communities context as it encourages collective leadership and it values trying different approaches and learning from them.

An example of how an action learning model works:

- ↳ The community forum provides the opportunity to identify key issues and priority areas for the community and local leaders who are interested in helping steer the group.
- ↳ The leadership group seeks partnerships and stakeholders to help address these key areas
- ↳ The initiative is launched in partnership which seeks to address these areas
- ↳ Evaluate and measure your success and challenges
- ↳ Use these learnings to refine and improve the initiative

## Shared leadership

As you start to meet regularly, you should find ways to share the leadership so that you don't become overwhelmed, but also so that the shared responsibility encourages further ownership and therefore commitment. This might mean letting go of how you as a leader see things progressing. Don't be afraid to step away from time to time too. Sometimes it's only in the absence of leadership that someone may feel compelled to step up.

## Case study: Building shared leadership

One way shared leadership was achieved in the Northern NSW group was to have a folder of information including minutes from each meeting, local information and end-of-life resources. The folder was shared around so at each meeting whoever was leading that meeting would add to the folder and would also pass it around for others to take any information or add anything they thought relevant. All the information was in there, completely accessible. It wasn't in one person's notebook or computer. As the Northern NSW lead described, 'I've focused on things that can be sustainable and don't need me to run them, for example our coffee mornings. The folder is a good way to hold people accountable and distribute information. It's pretty full at the moment with different leaflets and flyers and things and people just clear it out – which is good. It means the info is getting out there.'

## Partnerships and sustainability

While shared leadership can ensure community ownership and sustainability, equally significant are partnerships within the community. Some partnerships will organically come about through the networks of the action group, but it will also be an ongoing element to the work. Partnerships can open opportunities for your Compassionate Communities work to flourish in new areas and can also ease the burden of resourcing. There have been many examples through the NCCF where reaching out for support, such as with venues, catering or promotion, can have ongoing positive effects that lead to the development of a partnership.

'I think our relationship with the community centre is strengthened. Asking them "Can we use your facility" and then them coming on board and willingly advertising for us through their newsletters and website and so on on what we're doing. So, I think in that way we've got the word out in the community more than we had before.'

- Victoria Group

Partnerships can be really challenging, particularly if partners have differing values or motives. To help protect against this, it is important to keep the community at the core of the work. Any organisation or group interested in partnering on Compassionate Communities work must agree that the community is in the driver's seat and the leadership of the group must include community members and must constantly check in, refer and collaborate with the community as the work unfolds.

## Case study: Aligning values

One of the NCCF groups early on came up against some internal struggles with the direction and leadership of the group. Though the group had a good representation of multiple sectors within the community, there was a strong cohort who worked within the health system. This resulted in some predetermined expectations of how a group or network should be structured from the experience of the people working in health, many of them who had led or been on committees. Although it was fantastic to have such a wealth of experience in the group, the challenge was that it isolated those who were not from a health background and so did not have a shared language of formal group structure and leadership. This created a disconnect and a bit of tension around how to begin the project.

One exercise that was tried which helped to realign the group slightly was to map out the values of the leadership group and use these values as guiding principles for the group to operate with. They did this by using 'picture cards' (a widely available set of cards with diverse imagery on each). Each person in the leadership group selected three images to represent why they were passionate about improving end-of-life care in their community. From the three, everyone chose which one would be their number 1. These were then grouped into themes and value statements were developed from them.

This was an important exercise, at this early stage of the process, to determine shared values and ensuring everyone present was heard and recorded. It created a collegial space where both formal and informal experience were valued equally. Developing a document of guiding principles or a group vision can become a useful guiding document to return to regularly or to reflect on at the beginning of each meeting. It also becomes a guide for any new group members who join.

## Tools and initiatives

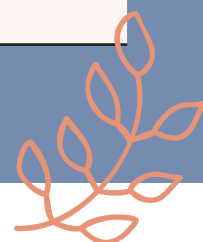
Over the page are some initiatives developed by The GroundSwell Project that have been run in multiple Compassionate Communities. They address common areas that communities have prioritised.

If any of these align with the direction your community decides to take, we'd love to hear from you and support you. These initiatives are designed to work in the interface between health and community to support the increase of death literacy and building community capacity.



## Compassionate Communities tools and initiatives

Initiative	Description
<b>Dying to Know Day</b>	Annual campaign day that encourages conversation and action around end of life. Everyday people host events each year creating safe spaces for these important conversations.
<b>Ten Things workshop</b>	A death literacy and end-of-life planning workshop for individuals and groups. It covers essentials including legal documents, funeral and burial options and builds confidence to have essential planning conversations with family and friends. Can be delivered online or face to face.
<b>Compassionate Workplace</b>	A suite of resources to equip workplaces to develop compassionate leadership and policies to enable compassionate workplace culture for staff experiencing loss.
<b>Health Connector Model</b>	A Health Connector is a community development worker, nurse or social worker placed in a healthcare or neighbourhood setting with the purpose of connecting with patients, helping them improve their support networks and addressing end-of-life planning.
<b>Community Connector Training</b>	Often linked to the Health Connector model (see above), Community Connectors are everyday citizens who guide and refer people to the Health Connector, local social groups and services, all of which can also be found online via an online directory.
<b>Creative Legacy</b>	An arts health program that brings artists and local community creatives into palliative care wards and other health settings to bring to life the stories of palliative care patients and their families. Stories of their lives and legacy are woven into artworks, poems, illustrations and songs and are given back to the patient and/or their family.
<b>Death Literacy Index and Community User Guide</b>	A population measurement tool that captures the level of death literacy of a population, group or community. It factors in education, background, lived experience and many other factors that may contribute to someone's ability to navigate and make informed choices about end of life. It can be used as a tool for policy and planning decisions and to take a snapshot of your community's death literacy.



# Death Literacy Index Community User Guide

The Death Literacy Index (DLI)<sup>17</sup> is a 29-question survey that can be used to measure a group or community's death literacy. The index consists of four scales of measurement:



Taking this survey as a group will give you a sense of your collective death literacy and where you sit in terms of the Australian national average. It is a way to communicate and understand the elements that combine to bring about death literacy, the group's areas of strength and what areas could be further developed.

The survey can be used once, to take a snapshot in time, or it can be applied before and after you trial an initiative to measure changes. First and foremost, it is a community development tool, built on the principles of a public health approach to palliative care. This means you will get more out of the index if you do it and discuss it as a purpose-driven community.

**Step 1. SURVEY.** In a community meeting if possible, plan how you will use the DLI. Consider the Dos and Don'ts below. Invite as many people as you can to take the survey. It will only take them three to five minutes to fill in and add up their answers.

**Step 2 and 3. SCORE.** Have someone transfer all of these results onto the Step 2 score sheet for all the participants and add up the totals. The Step 3 score sheet will help you to calculate the averages for the four scales and subscales and the full DLI. It will also assist you to scale your averages so that the scores for your group can then be compared to the Australian averages to see if your group is higher or lower. The score sheets can be accessed [here](#).

**Step 4. DISCUSS** these findings with your community/group and get their response and input. Is anything surprising or expected here? What did you learn? Is your group higher or lower than the Australian average? How does this make sense of the discussion in your community forums? Are there correlations or gaps?

**Step 5. PLAN.** How can these results and the conversation inform what we do next? You may notice some areas are higher than others and lower scores show areas of knowledge or skill that might be strengthened. Whether you are taking an educational approach or doing community development, you can use the DLI to guide your plan.


**Step 6. TAKE ACTION.** Once you have developed your plan with community members, make plans to take action. Keep working alongside your community and checking in about what is working or not working. The DLI can be used to inform decision-making along the way. See below for an example.

**Step 7. REFLECT AND SHARE.** Did your education or intervention make a difference? Go back to your community and discuss any changes picked up by the DLI. If things didn't change, why not? Make a plan. Discuss with your community. Repeat.


<sup>17</sup> The DLI User's Guide was prepared by Dr Kerrie Noonan for the Caring at End of Life research team, School of Social Sciences, Western Sydney University, and The GroundSwell Project.


**Optional step.** The DLI can be used to understand community changes in death literacy by using it before, during and after any education or intervention. Not everyone will use the DLI this way, but it might be useful for some projects that need to show outcomes over time.

## Some do's and don'ts.

 DO consider what other demographics might be helpful to ask about. We found these things were related to death literacy:

- Talking to neighbours and having someone to contact if you need help.
- Getting older, retirement and being widowed.
- Having children of any age, adults dependent on you, any religious or spiritual practice and a belief in an afterlife, or volunteering, working and training in end of life are also predictors of higher death literacy scores.

 DO look for interesting combinations, such as is your group higher than the Australian average when it comes to talking about death but lower on the hands on care subscale? How can talk transform into action?

 DON'T be black and white about how you interpret the scores – it's not about 'better' or 'worse than' the Australian average. It's about finding strengths to amplify in order to address the gaps. And remember anyone who has joined your group or come to your forum is already interested in the topic. They are likely to have higher Death Literacy than the Australian average so don't be surprised if your figures look good.

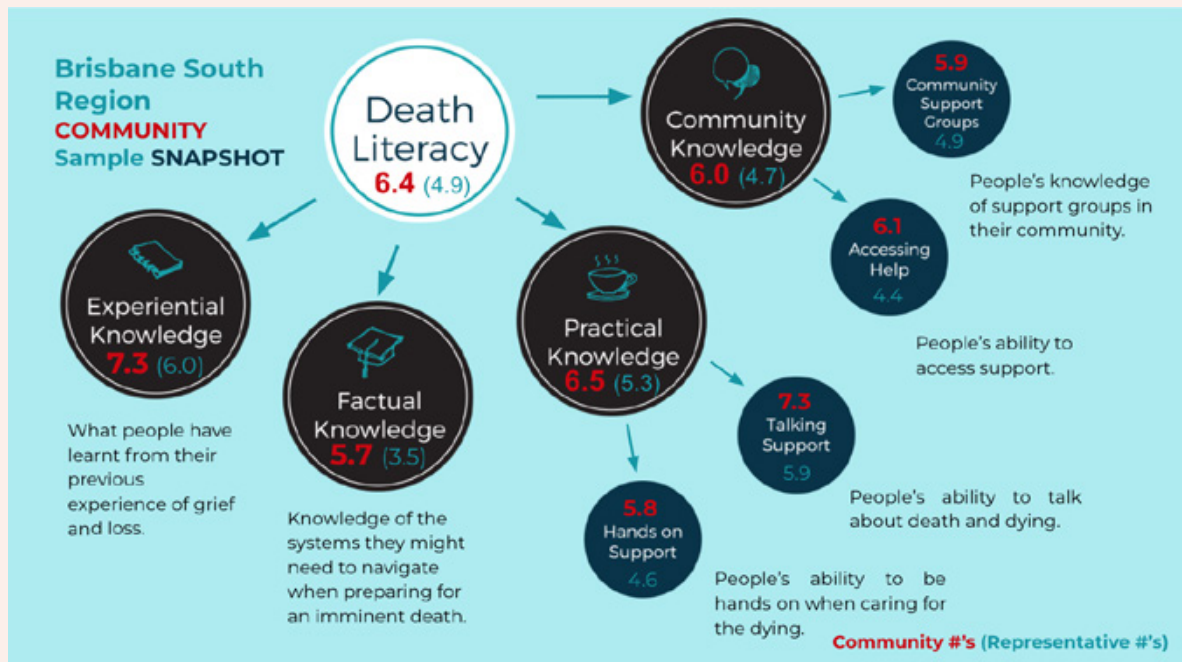
 DON'T make it too complicated. The DLI is designed to be a simple and easy way to look at death literacy in your community. It's meant to be a tool to community build. We encourage you to use it in conjunction with and alongside your group.

There are additional elements that can be added to the 29-scale DLI that can be used to take the research further in your populations. There are 18+ Actions and Attitudes scales that can give you more detailed information about your community's death literacy, and any number of demographic questions can be added at your own will. These additional items are outlined in the DLI report.<sup>18</sup> You can implement these yourself or with the help of the GroundSwell Project.

<sup>18</sup> Leonard, R., Noonan, K., Horsfall, D., Psychogios, H., Kelly, M., Rosenberg, J., Rumbold, B., Grindrod, A., Read, N., and Rahn, A. (2020). Death Literacy Index: A Report on its Development and Implementation. Sydney: Western Sydney University.

## Case study: Using the DLI to take action

In 2020 the DLI was rolled out in the Brisbane South PHN region. An initial workshop has been held to discuss the results with community members and palliative care sector stakeholders. A snapshot of the results are below:



And here are the GroundSwell initiatives that have been recommended in response to the survey:

<b>Contribution:</b> Dying to Know Day	<b>Collaboration:</b> Compassionate Communities: Toolkit and Community of Practice	<b>Navigation:</b> 10 Things to know before you go
<p>Dying To Know Day (August 8th) is an annual day of action dedicated to activating conversations and community actions around death, dying and bereavement. Throughout August, people are encouraged to host an event with their friends, family, workplace or community group etc. Events include anything from a film night to a dinner party, an information stall or a panel discussion. It could be a face to face event or online - if it sparks a conversation, it counts as an event!</p> <p>Dying to Know Day has shown to be a great to share stories and learn together. Death is not the taboo we think it to be and people flock to these events, keen to learn and develop knowledge and skills.</p>	<p>Compassionate Communities are communities in which everyday people play a stronger role in the care and support of people as they age and at the end of life. A globally recognised approach to improving the end of life experience by mobilising local networks, groups and services to work together.</p> <p>The Toolkit is a practical guide for any community leader or group who wants to instigate Compassionate Communities initiatives in their area using a community development approach.</p> <p>The Community of Practice is an online collegial space for anyone working on building compassionate communities.</p>	<p>This is a comprehensive 2 hour online workshop that empowers people with the knowledge and resources you need to plan well for the final stages of life. The digital learning environment leaves people feeling confident to have essential planning conversations with those that matter.</p> <p>This workshop educates on and explores end of life planning in an engaging, accessible way while recognising existing skills and experiences. This is a key program offered by GroundSwell that addresses the skills and information needed to navigate the system, know the laws, access care and undertake advance care planning.</p> <p>Knowledge of the systems needed to navigate the care needed for an imminent death was the lowest scale reported. The PHN reported that navigating skills continue to come up in different consultations (not just in end of life).</p>

## Evaluating as you go

One of the key recommendations from the research of the NCCF was the need to value alternative evidence of success in this work beyond purely quantitative data. Different, inclusive and accessible ways of sharing knowledge and experience of developing are vitally important. Stories and narratives are essential tools that can offer a more effective reflection of a community's experience.

During the NCCF, the Groundbreaker communities were offered different measurement tools to use if they found them helpful. They were also encouraged to explore what ways of capturing and measuring their work made sense for them.

For some, this meant quite detailed minutes from organising committee meetings. For another, this meant a regular blog and newsletter sharing the progress of the group.

Below are two techniques of measurement and reflection that the Western Sydney University Caring at End of Life research team shared with the Groundbreakers.

### Photo-voice critical moments and turning points

Photo-voice involves using imagery on a regular basis as a visual representation of an important moment or turning point for your community in doing this work.

The photo could be about your vision for the project, something that was successful, or your worries about the project. It could be a photo which shows a particular barrier you have come across, or it could represent the joy of connecting with others and progressing this work. It could be an 'aha' moment. It does not matter what it is. What does matter is that you use this opportunity to reflect upon what you have been doing, choosing the most important thing you want to say at this time. The Groundbreakers would present their photos in research group meetings. You might use them as internal documentation or the basis of a report or stakeholder update.

1. Give your photo a title.
2. Then write a brief narrative/description of it: what it means, why this image, what is it you want to say.

If possible, you could do this as a group activity to bring together the group responsible for the Compassionate Communities work in your area.

### Networking mapping exercise

A great way to show progress of a Compassionate Community developing is to show the increase in connections and links across sectors of the community. Network mapping is a technique that captures the connections that are made and how they grow in strength and numbers over time. Many of the Groundbreaker groups did this exercise at the initial forum meeting and again towards the end of the project to show growth over time.

It's a great thing to do at the beginning of your project and do again at the end, or after a few months. See how things have changed and progressed. Several of the NCCF communities included this exercise as part of their community forum. You could also do it in your follow-up meeting with a smaller group.

## What you need

- Butchers paper or a whiteboard
- Black, red, yellow and blue markers

## Instructions

1. In BLACK, write down (reasonably geographically) as many organisations, services, groups, businesses etc. in the local area that could support someone dying, caring for someone dying, or bereaved.
2. In BLACK write down (anywhere) your first name and job title/place of work.
3. CHOOSE a colour from below and draw a line between yourself and EACH other entity that you know:

**RED** means you know/work with the entity REALLY WELL

**BLUE** means you are fairly familiar with them. You know or work with this group or organisation an average amount.

**YELLOW** means you know or work with this group or organisation in a limited capacity, for example, you've maybe only just heard of them.



*Have fun and be creative with how you display it.  
This was one NCCF group's colourful interpretation.*



## Questions for reflection

Sharing the leadership of the work is important because ...

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What are some examples of effective partnerships that I have experienced before?

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What tools or initiatives stand out to me and why?

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What are some ideas of ways to evaluate and record as the work progresses?

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# Final thoughts

At the time of publication, December 2020, the pandemic has highlighted the importance of caring relationships and localised support. The Compassionate Communities model provides a framework for how to make meaningful change to how people experience this kind of support, with actions and initiatives that work with the strengths of each community.

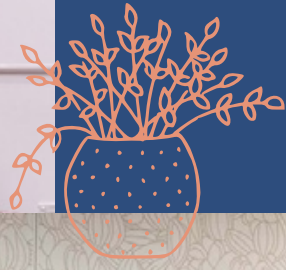
This toolkit and the research findings that accompany it reflect the real challenges and triumphs that come from this work. Communities are the experts of their own lives and they are essential in navigating the progress towards better end-of-life care.

As we emerge from a year that has pushed our health services to the brink, we are reminded of the stark need to build capacity for our communities to engage and respond to our ageing and dying members. The new normal must include all of us finding our place and playing our part. It can no longer be left up to our health services alone. It takes us all and the time is now.

We hope this toolkit helps to shift the dial on how we think about and invest in communities to support ageing, dying and bereavement.

**The GroundSwell Project**







 [www.thegroundswellproject.com](http://www.thegroundswellproject.com)