

Bringing Death Back into Life:

An Exploratory Report for Compassionate Communities in Lincolnshire

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Dedication

In memory of Alan Walker (1951-2026), partner of Jacqui Winn, who died suddenly at home during the writing of this report. A defining feature of Alan's life was the building of community. He did this through football coaching, organising music festivals, leading the Nottingham Writers' Studio and most recently, setting up the Burton Road and District Residents' Association in Lincoln.

Acknowledgements

We wish to thank over 30 people in health, social care, voluntary and community organisations who gave up their time to speak to us. We had the fortune of spending our summer in conversation with others and it has been heartening and encouraging to have met so many good people. We were not able to talk to everyone we wanted to in the time we had, but this is just the start of the conversation.

Max Gopal gratefully received funding from the National Institute for Health and Care Research's (NIHR) New Medical Schools Intercalated Degrees and Internships Programme.

AI transparency statement

The drafting of some sections of this report was assisted using generative AI tools provided by the University of Lincoln. This was principally to help synthesise and summarise the literature, transcribe meeting conversations and produce concise case study summaries. At all times, AI was only used on literature that we manually sourced, selected and directed it to work on. AI generated text was read through, fact-checked, referenced and redrafted to our satisfaction. Most of it has *not* ended up in the finished report. It was the first time we have worked in this way for research purposes and in the limited timeframe we had, found it very useful. AI produced several errors and misinterpretations, which we have removed or corrected, and we take full responsibility for the final version of this report.

There is death in life, and it astonishes me that we pretend to ignore this: death, whose unforgiving presence we experience with each change we survive because we must learn to die slowly. We must learn to die: That is all of life. (Rainer Maria Rilke, 1907)¹

¹ Rilke, R. M. (2018). *The dark interval: Letters for the grieving heart* (U. Baer, Trans. & Ed.). Bloomsbury Publishing. p.1.

Introduction

This report is the outcome of a short exploratory project about care for people who are dying. Our intention and invitation was to learn and think about what the public health concept of ‘compassionate communities’ means for Lincoln and Lincolnshire.

Compassionate Communities are a form of ‘public health palliative care’² that reframes death and dying as primarily a *social* experience rather than a physical experience. In practice, they are usually different types of community development projects that aim to improve a population’s understanding and experience of death, dying, loss, and caregiving. Over two decades of research literature argues that where this is achieved, it can be transformative, socially and individually. Advocates of this approach argue that *end-of-life care is everyone’s responsibility*, but what does that mean in practice, in the lives of individuals and the life of a community?

Our work links directly to Ambition 6 of the national palliative care framework (2021-2026):

“Each community is prepared to help. I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.”

Research undertaken in 2022 found that Ambition 6 “was least likely to be prioritised, despite people welcoming the focus on community in national guidance.”³ We wanted to understand, without judgement, what resources and activities are present in Lincolnshire to achieve Ambition 6.

Some cities have adopted a Compassionate City Charter. A Compassionate City is one where workplaces, trade unions, schools, places of worship, hospices, nursing homes, museums and art galleries collaborate and co-operate to effect social change around support for those of us experiencing dying, death and loss. Through our exploratory research, we wanted to understand what more we can do to make Lincoln a compassionate city, where our civic institutions and organisations enable all of us to live well within our communities to the end of our lives.

As well as reviewing a large body of literature on compassionate communities, death literacy and related topics, we have been fortunate to talk with people in health, social care and the voluntary and community sectors to understand their perspectives and the work they are doing to support dying people and their carers. We summarise those informal conversations later in the report and want to acknowledge here their expertise, enthusiasm and interest in the work we have been doing.

Although we have undertaken this research as paid academics within an institution, talking to professionals in health and social care, we have tried to distance ourselves from the world of professional services and remain *amateurs*; that is, curious, enthusiastic, a bit naive at times, and motivated first and foremost by love.

² <https://www.phpci.org/> ; <https://phpcuk.org/>

³ Borgstrom, E., Jordan, J., & Henry, C. (2023). Ambitions for palliative and end of life care: Mapping examples of use of the framework across England. *BMC Palliative Care*, 22, Article 83, p. 1.
<https://doi.org/10.1186/s12904-023-01207-3>

Recommendations

An ‘exploratory’ report suggests a new terrain, yet some of what we recommend may feel like well-trodden ground. If that is the case, think of us as turning over the earth to cultivate conversations, sow the seeds of new collaborations and shine light on a neglected patch of *life*.

We have aligned our recommendations with the Lancet Commission’s “five principles of a ‘realistic utopia’, a new vision of how death and dying could be.”⁴ Each recommendation is intended to strengthen, connect and make more visible existing activity across Lincolnshire; they are *not* exclusive of one another. In many cases, the necessary organisations, partnerships and policy commitments already exist. From what we have found, the challenge is to coordinate, extend and sustain them through a shared public health palliative care framework that prioritises education and community effort.

1. The social determinants of death, dying and grieving are tackled

1.1 Make equity and early identification central objectives

Develop a Compassionate Lincolnshire programme that prioritises people who are least likely to receive timely palliative care or community support, including those living in deprived, rural and coastal communities; people experiencing homelessness or imprisonment; minority ethnic groups; people with dementia, learning disabilities or non-cancer diagnoses; and those without reliable social networks.

This recommendation directly supports existing priorities within the Lincolnshire Palliative and End of Life Care Strategy 2023-2028, the Lincolnshire ReSPECT Policy, the DLN Population Health Strategy, and the Neighbourhood Health agenda. Existing community connector, neighbourhood teams, social prescribing and public health programmes already provide a foundation for this work.

1.2 Support for unpaid carers is essential

Identify, prepare and support unpaid carers through practical guidance, peer support, respite information, emergency planning, benefits and employment advice, and continuing contact during bereavement. Give particular attention to people who may not identify themselves as carers, including young carers and those combining employment with care.

This recommendation builds on substantial existing activity through Carers First, the Lincolnshire Carers Service, St Barnabas Wellbeing Services, Healthwatch Lincolnshire's carers programme, and the Joint Health and Wellbeing Strategy priority on carers.

1.3 Design for Lincolnshire’s geography

Develop a network of locally embedded initiatives across Lincoln city, market towns, coastal communities and rural areas. These should operate at small scale, connected through light county-wide coordination rather than a centralised delivery model.

⁴ Sallnow, L., Smith, R., Ahmedzai, S. H., Bhadelia, A., Chamberlain, C., Cong, Y., Doble, B., Dullie, L., Durie, R., Finkelstein, E. A., Guglani, S., Hodson, M., Husebø, B. S., Kellehear, A., Kitzinger, C., Knaul, F. M., Murray, S. A., Neuberger, J., O’Mahony, S., ... Wyatt, K. (2022). Report of the Lancet Commission on the Value of Death: Bringing death back into life. *The Lancet*, 399(10327), 837–884.
[https://doi.org/10.1016/S0140-6736\(21\)02314-X](https://doi.org/10.1016/S0140-6736(21)02314-X)

This approach aligns with current Integrated Neighbourhood Team development, emerging Neighbourhood Health Centres, Wellbeing Lincs, district council community development activities, LocalMotion Lincoln, and established community-led initiatives across the county.

2. Dying is understood as a relational and spiritual process rather than simply a physiological event

2.1 Reframe advance care planning as a relational process

Support advance care planning and ReSPECT conversations that address relationships, identity, culture, spiritual concerns, sources of meaning and the people whom an individual wishes to involve, alongside clinical preferences. Trained community volunteers could support understanding and preparation while leaving clinical responsibility with professionals.

This recommendation reinforces existing Lincolnshire ReSPECT, Advance Care Planning and EPaCCS policies, while extending the personalisation principles already embedded within the It's All About People (IAAP) programme and 'What Matters to You' conversations.

2.2 Develop an inclusive pastoral and spiritual care network

Bring together hospital, hospice, university, prison and armed forces chaplaincies, faith communities, humanist organisations and culturally specific groups to improve access to spiritual and existential support for people of all faiths and none. The network should also advise on culturally appropriate practices around dying, funerals and bereavement.

This would build on existing provision already offered through ULH Chaplaincy, St Barnabas Spiritual Care, Lincoln Cathedral Chaplaincy, Lincoln Prison, the University of Lincoln Multi-Faith Chaplaincy, and the Lincolnshire Faith Council.

2.3 Build relational understanding through workforce development, arts and culture

Work with St Barnabas Hospice and Lincolnshire Community Health Services to deliver relevant end-of-life learning across clinical services, funeral services, care homes, voluntary organisations and community networks. Complement formal training with storytelling, music, visual art, food, performance and local memorial practices that allow people to explore mortality, cultural difference and the meaning of care in accessible, non-clinical settings.

This extends activity already taking place through St Barnabas education and wellbeing programmes, community development initiatives, arts-based approaches found in national compassionate community programmes, and emerging public conversations about death literacy and bereavement. It aligns with national end-of-life workforce frameworks and Lincolnshire's broader personalisation agenda.

3. Networks of care lead support for people dying, caring and grieving

3.1 Establish shared governance and sustained community-development capacity

Create a coordinating partnership involving residents and people with lived experience. Invest in skilled community-development workers, supported by multi-year funding,

professional development and succession planning, to build trust, map assets, connect organisations and nurture local leadership.

This recommendation builds directly on existing mechanisms including the Lincolnshire ICS Co-production Framework, LVET, the ICB People and Communities Strategy, and established community-development expertise within organisations such as Lincoln City Council, Every-One, CVS Lincolnshire, LocalMotion Lincoln and DevelopmentPlus.

3.2 Pilot coordinated circles of care and companion pathways

Test voluntary, consent-based circles of care through which people who are dying can mobilise support from family, friends, neighbours, workplaces and community organisations. Develop a coordinated pathway linking befriending, pastoral care, bereavement support, end-of-life companions and potential doula provision. Safeguarding, supervision, role boundaries, expenses and referral arrangements must be established before expansion. These roles should complement, not replace, professional or statutory care.

Lincolnshire already has related activity through Marie Curie Companions, St Barnabas volunteers, bereavement services, community connectors and previous co-production work exploring end-of-life doulas. The recommendation is therefore to learn from and develop these approaches rather than start from nothing.

3.3 Embed end-of-life support within social prescribing

Make dying, bereavement and carer support explicit categories within Lincolnshire's existing social-prescribing infrastructure, including It's All About People, HAY Lincolnshire, Connect to Support and community connector services. Train link workers and ensure that relevant community services are included in local directories and referral pathways. Recognise that the social prescribing model favours those who are mobile and in better health. Compassionate communities bring networks to people rather than requiring people to go to established networks.

3.4 Recognise care homes as community assets

Support care homes to act as neighbourhood hubs, learning sites and sources of practical knowledge about dying and bereavement. Learn from the work of those care homes that provide exemplary end of life care.⁵ Provide death-literacy education for the whole workforce and, where appropriate, support care homes to host community conversations, remembrance events and local support activities.

This reflects findings from local stakeholder conversations, the Older People's Strategy, Healthwatch reports and existing examples of community-facing care homes within Lincolnshire. It also complements neighbourhood health and ageing well priorities.

4. Conversations and stories about everyday death, dying and grief become common

4.1 Develop a community-based death-literacy programme

Create an adaptable programme for residents, carers, volunteers and non-specialist workers, informed by the Death Literacy Index. It should address conversations about dying and grief,

⁵ e.g. care homes with GSF accreditation <https://www.goldstandardsframework.org.uk/>

practical support, advance care planning, local services, what happens after a death and self-care while caring. Delivery should include recurring, locally hosted conversation spaces with trained facilitators and referral routes.

This recommendation aligns with Ambition 6 of the national Ambitions framework, existing EOLC public information resources, St Barnabas education activity, and national developments in community end-of-life capability frameworks.

4.2 Work with schools, colleges and the university

Develop age-appropriate education about change, loss, bereavement, caregiving and mortality. Teachers and pastoral staff should receive training and support rather than simply additional content.

This would build on recent statutory curriculum developments, University of Lincoln teaching and community engagement activity, youth work infrastructure, and the growing recognition of bereavement education nationally.

4.3 Create a public programme of stories, arts and events

Establish an annual programme of exhibitions, festivals, talks, performances, memorial activities and community reporting that makes local experiences of caring, dying and grieving visible. A dedicated community-reporting strand could inform commissioning and public understanding.

This can draw on existing community-reporting work through IAAP and People's Voice Media, creative partnerships across Lincolnshire, LocalMotion Lincoln, faith organisations, St Barnabas and local cultural institutions.

5. Death is recognised as having value

5.1 Establish compassionate dying as a long-term civic commitment

Develop and adopt a Lincoln-specific version of the Compassionate City Charter, supported by Lincoln City Council, the ICB, Lincolnshire Public Health, the University of Lincoln and community partners. Adoption should follow demonstrable action and establish reviewable commitments across education, employment, care, culture, neighbourhood life and public remembrance.

This recommendation supports and gives practical expression to the consistent Lincolnshire strategic ambition that people should “live, age and die well”, which already appears across the Joint Health and Wellbeing Strategy, Integrated Care Partnership Strategy, Joint Forward Plan and ICB strategies.

5.2 Create inclusive opportunities for remembrance and shared learning

Work with communities to develop inclusive rituals, events and spaces through which deaths can be acknowledged and lives remembered. Recognise people with experience of dying, caring and grieving as contributors to education, community development and service improvement.

This would build on existing hospice bereavement services, faith communities, chaplaincies, community organisations and memorial practices already operating across Lincolnshire while creating stronger connections between them.

5.3 Evaluate cultural, relational and equitable change

Assess changes in death literacy, confidence, social connection, mutual support, organisational practice and experiences of caring and bereavement. Combine the Death Literacy Index with qualitative evidence, network mapping and equity monitoring. Service use, hospital admissions, place of death and financial savings may be relevant, but should not become the sole measures of success.

This recommendation aligns with existing population health, co-production and community-development approaches in Lincolnshire, while complementing the outcome measures already used within palliative care, neighbourhood health and integrated care programmes. It should add community-level indicators rather than duplicate clinical performance metrics.

The rationale: Beyond statistics

Compassion does not need to be justified by statistics. The dying person, let us call her Margaret, and those close to her have no use for demographic detail; they do not need to know that more people are dying in the UK than are being born⁶, or be told that life expectancy has increased but healthy life expectancy has decreased.⁷ Margaret observed this in her husband, who died slowly from COPD five years ago. The last ten years of her long life has shown Margaret how things have changed since she was born in 1946. Then, dying was more often an acute event at home, but now more frequently occurs at the end of chronic illness, multimorbidity and frailty, in a hospital or care home.⁸ She is unaware that she was fortunate to be placed on the palliative register, something her daughter, Jane, pursued after their experience with her dad.⁹ As she is dying, it is now meaningless to Margaret that almost a quarter of Lincolnshire's population are over the age of 65 and by the time her daughter dies two decades later, an even greater number of people will be seeking compassionate care from the people around them.¹⁰ Margaret once had a large circle of friends her own age, but this has diminished as they grew older and her neighbourhood changed. Her daughter, too, has felt increasingly isolated since she retired early to care for her mum.¹¹ Margaret is not interested in the numbers, but she is aware that the city where she has lived for most of her adult life has become younger and more ethnically diverse. She has experienced this most recently in the health and social care she has received and is grateful for.¹² Margaret is at

⁶ Deaths now exceed births in the UK.

<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2024based> In 2025, the Total Fertility Rate was 1.39 children per woman in England and Wales. The TFR in Lincoln was 1.2.

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthsummarytablesenglandandwales/2025finalrates#fertility-rates> There were around 35% more deaths than births registered in Lincolnshire (2023 births=5998/2024 deaths=9263). <https://lhih.org.uk/jsna/>

⁷ The healthy life expectancy of a woman in Lincolnshire has decreased to 58.6 years.

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/healthstatelifeexpectanciesuk/between2011to2013and2022to2024>

⁸ ONS Causes of death over 100 years

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/causesofdeathover100years/2017-09-18> In 2024, 39.7% of deaths in Lincolnshire occurred in hospital; 28.8% occurred at home; 24.5% occurred in care homes; 4.9% in hospices

<https://fingertips.phe.org.uk/profile/end-of-life/data#page/4/gid/1938132883/pat/221/par/E54000013/ati/66/are/E38000238/iid/93474/age/1/sex/4/cat/-1/ctp/-1/yr/1/cid/4/tbm/1>

The Lincolnshire Palliative and End of Life Care Strategy 2023-2028 states that 60.3% of people who died had recorded their Preferred Place of Death but only one third achieved it, but for those receiving specialist palliative care, around 95% of patients had their place of care and death documented and 89% achieved it. <https://lincolnshire.icb.nhs.uk/documents/strategies-and-plans/lincolnshire-palliative-and-end-of-life-care-strategy/lincolnshire-palliative-and-end-of-life-care-strategy-2023-2028/?layout=file>

⁹ *The Lincolnshire Palliative and End of Life Care Strategy 2023-2028* indicates there were over 6650 people on the palliative care register. The report also states that “40.2% of patients who died were not on the PEOL register, but died of conditions where palliative care would have been expected.”

¹⁰ Lincolnshire's aged 65+ population is projected to grow from 24.14% in 2024 to 37.4% in 2042.

<https://lhih.org.uk/jsna/>

¹¹ Data on social isolation and loneliness varies across the city but is most markedly different across the county. For a visual comparison, see <https://lincolnshirecf.co.uk/social-isolation-and-loneliness/> 48.8% of social care users aged 65+ have as much social contact as they would like. 81% of carers have felt lonely or socially isolated as a result of their caring role <https://tacklinglonelinesshub.org/wp-content/uploads/2021/12/The-world-shrinks-carer-loneliness.pdf>

¹² Data for the city of Lincoln's adult social care workforce could not be located. A summary for Lincolnshire indicates that in 2024/25 there were around 24,000 posts, of which 1200 were vacant. In the East Midlands region, if the workforce grows proportionally to the aging population, the number of posts will grow by

home, where she wants to be, cared for by her daughter and receiving palliative care. What could be unusual about that? Yet she has a strange sense of feeling ‘lucky’ to die in this way. Margaret and her family have not read the statistics, but they have lived long enough to know that the end of life is marked by the same inequalities as throughout life. Why should we expect it to be anything other?¹³

Death: In denial, a taboo, or valued?

There is an assumption, often repeated in the conversations we have had, that death is a taboo subject and most of us would rather not think about it, let alone talk about it. Attitudes towards death in the UK have been studied for several decades and present a much more complex picture. Over 40 years ago, Kellehear (1984) questioned whether we are a ‘death-denying’ (i.e. avoiding) society, concluding that while some of us, at some times in our lives, may avoid the subject, we are not a death-denying *society*.¹⁴ The concept of the ‘death system’, discussed below, helps us think about how the city of Lincoln organises around death and determines the conditions, circumstances and often the nature of our death, too. Walter (1991) questioned whether death is a taboo (i.e. forbidden to talk about) and observes that two key institutions – medicine and the media – control our interpretation and ritualisation of death as a largely individual, psychological experience narrowly centred around grief.¹⁵ Consequently, we live largely ignorant of the full experience of dying and death and the ‘taboo’, such as it is, is a stereotype of social fear which denies the differences among individuals, social status and cultural groups.

More recently, in a systematic review of research about public attitudes to death and dying in the UK, Cox et al. (2013) concluded it was impossible to develop evidence-based policy for end-of-life care because there was simply not the volume, depth and quality of research needed to underpin it.¹⁶ A decade later, Marie Curie funded research into public attitudes to death, dying and bereavement in the UK (Goss, et al. 2024).¹⁷ They found that just over half of us think we do not talk about death and dying enough. Around two-thirds of us said we

34% by 2040. The staff turnover rate was estimated to be 30.2%, which is higher than the regional and national averages. 79% of Lincolnshire’s adult social care workforce is female, with an average age of 43.6 years old. An estimated 79% are British, 16% of non-EU nationality and 5% of EU nationality.

¹³ Lincolnshire’s ReSPECT Policy (2025) highlights that “It is estimated that around 1-2% of the population should be recognised as palliative. In Lincolnshire recognition is 0.67%... Around 43% of people have been placed on the palliative register in the last 4 weeks of their life – this late recognition is higher in areas of higher deprivation.” This is because a “combination of an ageing population, rural geography and areas of high socioeconomic deprivation creates a challenge to delivering high quality and effective treatment and preventative services.” Nationally, 1 in 4 deaths are cancer related but 1 in 2 people receiving palliative care are on the cancer register, “suggesting a low recognition of other diagnoses.” Women are more likely (54.9%) to be on the palliative register than men (45.1%) and ‘White other’ residents have a disproportionately low recognition compared to ‘White British’. <https://www.itsallaboutpeople.info/latest-news/refreshed-respect-policy-lincolnshire>

¹⁴ Kellehear, A. (1984). Are we a “death-denying” society? A sociological review. *Social Science & Medicine*, 18(9), 713–721. [https://doi.org/10.1016/0277-9536\(84\)90094-7](https://doi.org/10.1016/0277-9536(84)90094-7)

¹⁵ Walter, T. (1991). Modern death: Taboo or not taboo? *Sociology*, 25(2), 293–310. <https://doi.org/10.1177/0038038591025002009>

¹⁶ Cox, K., Bird, L., Arthur, A., Kennedy, S., Pollock, K., Kumar, A., Stanton, W., & Seymour, J. (2013). Public attitudes to death and dying in the UK: A review of published literature. *BMJ Supportive & Palliative Care*, 3(1), 37–45. <https://doi.org/10.1136/bmjspcare-2012-000203>

¹⁷ Goss, S., Sivell, S., Harrop, E., & Noble, S. (2024). *Public attitudes to death, dying and bereavement in the UK re-visited: 2023 survey*. Marie Curie. <https://www.mariecurie.org.uk/document/survey-death-dying-bereavement-2023>

would feel comfortable discussing topics related to end of life, yet most had not actually had such conversations. When we do talk about death and dying, about three-quarters of us would prefer to talk to family and friends about it, but as we approach the last years of our lives, we become more reluctant to talk about dying with those close to us.

The survey provides important evidence about the attitudes and preferences we have about how our lives end – it clearly does matter to us when prompted – but the conversations we wish we could have with people we know are largely absent. A range of reasons are given for this, including not wishing to distress our family and friends, feeling unable to anticipate the future, and trusting that those close to us will make the right decisions in the end. The Marie Curie research challenges the perception of death and dying as taboo. Most of us do not think it is a forbidden subject of conversation but still most of us don't talk about it in any meaningful way and so a common aspect of our humanity – common to every *living* thing – is left unexplored, individualised and unshared. Not talking about death is to remain silent on a defining feature of life.

The extraordinary *value* of death is explored in the Lancet Commission's 2022 report, *The Value of Death: bringing death back into life*. The authors argue that death has value because

“without death there would be no life. Death allows new ideas and new ways. Death also reminds us of our fragility and sameness: we all die. Caring for the dying is a gift, as some philosophers and many carers, both lay and professional, have recognised. Much of the value of death is no longer recognised in the modern world, but rediscovering this value can help care at the end of life and enhance living.”¹⁸

It is both end-of-life care and enhancing life socially, spiritually and emotionally, that has motivated our work on this report and while life and death are rightfully matters for quiet introspection and private reconciliation, there remains much value in bringing the subject of death back into life and into our homes, workplaces, schools and communities.

Finding the right language

When are we ‘dying’?

We are less concerned about ‘death’ than we are about ‘dying’. Death, for the individual is the cessation of life, and for some of us the end of everything. For those of us with a faith, death is the beginning of something new. At different times in history, in different cultures, ‘death’ has been conceived more like our understanding of ‘dying’ today, that is, a process or journey that occurs over time and transcendental space. But when are we dying? When we first feel the lump? When we are told we are terminally ill? When we have a ‘life-limiting illness’? When we understand and accept we are dying? Or when we are ‘actively dying’ in the final days and hours of our life? From a biological perspective, dying may denote the organic collapse and failure of a body, when medical interventions can no longer halt or reverse that process. Yet, from sociological (outwards and relational) and psychological

¹⁸ Sallnow et al. (2022)

(inwards and individual) perspectives, dying is the final, active, and conscious living chapter of human life.¹⁹

Death System

Much recent policy and strategy around end-of-life care is concerned with personal choice, and for good reason. However, much of our understanding and experience of death is culturally determined by what is referred to in the research literature as the ‘death system’. This is defined as “the interpersonal, sociophysical, and symbolic network through which an individual’s relationship to mortality is mediated by society.”²⁰

A simple presentation of the death system is that in a society, like that of Lincoln, England, there are **people, places, times, objects** and **symbols** that make up the *components* of the death system. Then, there are the *functions* that those components have: To give **warnings and predictions** of threats to life; to **prevent** death; to **care** for the dying; to **dispose** of the dead; to work toward **social consolidation** after death; to help **make sense** of death, and to bring about **socially sanctioned killing**. So, for example, an undertaker (people) helps arrange the funeral (social consolidation) of the dead, as does a crematorium (place) which is also a site for the function of disposing of the dead. When a city like Lincoln is studied using the framework of the death system, we find that death is all around us even though we may look past it (e.g. a memorial on a street corner) or interpret the function differently (e.g. a pharmacy).

We have begun to plot Lincoln’s death system on a map and invite you to use it in conversation and suggest additional markers: <https://lncn.ac/deathsystem>

Death Literacy

Death literacy is the ability to have conversations about death and dying; knowing how to care for someone who is dying; understanding what to do when someone has died and knowing where and who to go to for support if you are caring for a dying person. The concept originated within public health approaches to palliative care. Death literacy frames mortality as a shared, relational social process rather than an exclusively biomedical or institutional event. The researchers who originally developed the concept define death literacy as:

“a set of knowledge and skills that make it possible to gain access to understand and act upon end-of-life and death care options. People, and communities, with high levels of death literacy have context-specific knowledge about the death system and the ability to put that knowledge into practice.”²¹

¹⁹ See: Kellehear, A. (2007). *A social history of dying*. Cambridge University Press and Kellehear, A. (2014). *The inner life of the dying person*. Columbia University Press.

²⁰ Kastenbaum, R., & Moreman, C. M. (2024). *Death, society, and human experience* (13th ed.). Routledge. <https://doi.org/10.4324/9781003182122>

²¹ Noonan, K., Horsfall, D., Leonard, R., & Rosenberg, J. (2016). Developing death literacy. *Progress in Palliative Care*, 24(1), 31–35. <https://doi.org/10.1080/09699260.2015.1103498>

A person's or a population's death literacy can be measured by the *Death Literacy Index* (DLI-R).²² The Index is a set of 29 questions divided into Practical Knowledge, Experiential Knowledge, Factual Knowledge and Community Knowledge. (see Appendix 1 for the full set of questions).

Since its development, researchers in the UK have used the DLI-R to measure the level of death literacy among the population²³ and regionally.²⁴ In our view, the DLI-R is a very useful tool to use in small scale settings to benchmark a cohort of staff or volunteers, guide conversations in a workshop setting, for curriculum development of death literacy training or for personal reflection and understanding of one's readiness to care for a dying person or support their carer.²⁵ The Death Literacy Index has become a key community development and evaluation tool in compassionate community initiatives.²⁶

Compassionate Communities

Compassionate Communities refers to a public health paradigm in end-of-life care that frames serious illness, dying, caregiving and bereavement as universal social experiences rather than predominately clinical events. Dying is perceived as a social experience with a physical dimension rather than a physical experience with a social dimension.²⁷ The concept borrows from the World Health Organisation's Healthy Cities framework and has, over two decades, been extensively theorised and put into practice, offering examples of what is also understood as 'public health palliative care'.²⁸ A common, evidence-based assertion is the '95% rule':

"Overall... dying people spend less than 5% of any one day in front of a doctor or nurse... For dying patients, their caregivers, and the bereaved, this will always mean that over 95% of their time is spent alone, with friends and other family, with neighbours or work colleagues, with animal companions, or with the internet or the television."²⁹

²² Noonan, K., Grindrod, A., Shrestha, S., Lee, S., Leonard, R., & Johansson, T. (2024). Progressing the Death Literacy Index: The development of a revised version (DLI-R) and a short format (DLI-9). *Palliative Care and Social Practice*, 18, Article 26323524241274806. <https://doi.org/10.1177/26323524241274806>

²³ Diggle, M. F. J., Johansson, T., Davies, J. M., Heaps, K., & Sleeman, K. E. (2026). Associations between sociodemographic factors, experience of death and dying, and death literacy: A nationally representative cross-sectional study. *Palliative Care and Social Practice*, 20, Article 26323524261473937. <https://doi.org/10.1177/26323524261473937>

²⁴ Peryer, G., Puri Sudhir, K., Wagner, A. P., & Blake, J. (2026). Mapping death literacy in the East of England: A cross-sectional survey with qualitative insights to inform public health strategy. *Palliative Care and Social Practice*, 20. <https://doi.org/10.1177/26323524261443547>

²⁵ Noonan, Kerrie, and Niki Read. 'Death Literacy as Community Practice'. In *Compassionate Communities in Action*, 1st edn, by Emma Hodges and Manjula Patel. Routledge, 2026. <https://doi.org/10.4324/9781003621348-24>.

²⁶ Hodges, E., & Byron, J. (2026). Death literacy in practice: Case studies from the UK. In E. Hodges & M. Patel (Eds.), *Compassionate communities in action: Global stories of care, loss and connection*. Routledge. <https://doi.org/10.4324/9781003621348-25>

²⁷ Kellehear, A. (2022). The social nature of dying and the social model of health. In J. Abel & A. Kellehear (Eds.), *Oxford textbook of public health palliative care* (pp. 22–29). Oxford University Press. <https://doi.org/10.1093/med/9780198862994.003.0004>

²⁸ Abel, J., & Kellehear, A. (Eds.). (2022). *Oxford textbook of public health palliative care*. Oxford University Press. <https://doi.org/10.1093/med/9780198862994.001.0001>

²⁹ Kellehear, A. (2022).

On this basis, advocates argue that end-of-life care is everyone's responsibility. It is the quality of that *social* experience – the care and companionship from the people who matter to the dying person – that end-of-life care should be re-orientated around.

To enable this, work to build compassionate communities is fundamentally *community development* work. This cannot be emphasised enough and is found throughout the case studies included later in this report. A common approach is asset-based community

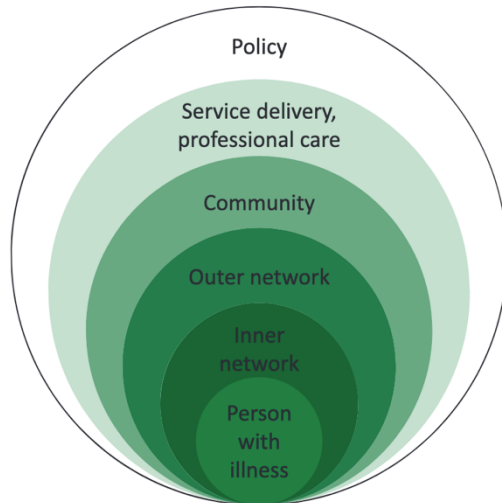


Figure 1: Circles of care (Abel, 2018)

development (ABCD) and a social ecological framework to map and build 'circles of care' (Figure 1).³⁰ These encompass 'inner' informal networks (family and close friends providing direct care) and 'outer' structural networks (neighbours, local businesses, schools, and workplaces offering practical, social, and emotional assistance) operating alongside formal healthcare providers (Figure 2).³¹ These community development initiatives are seen as collective efforts to develop individual capacity, group strategies, and public policies that mitigate suffering, improve death literacy, and promote equity and inclusion.

Alongside existing general and specialist palliative care and new compassionate community initiatives, the major sectors of civic society: workplaces,

schools, places of worship, hospices and nursing homes, museums and art galleries, should be enlisted to recognise and support these efforts, too. A *Compassionate City Charter* has been drawn up to guide this civic commitment and be adapted by cities like Lincoln (see Appendix 4).

Palliative care: A realistic utopia

Joan was eighty when she was told that her heart failure had entered its final stage. She had lived in the same terraced house for thirty years and wanted only one thing: to remain there for as long as possible. At first, the news felt overwhelming. Breathlessness confined her

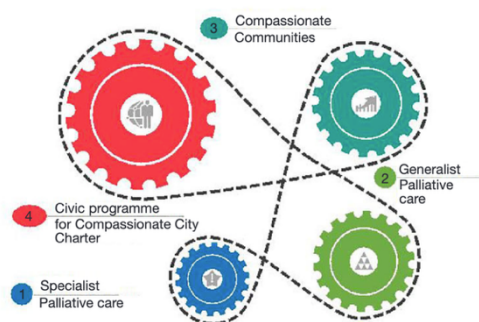


Figure 2: Palliative care - the new essentials (Abel, 2018)

increasingly to the downstairs rooms, and she worried less about dying than about becoming a burden to her daughter, Sarah, who until recently had worked full-time and was now her primary carer.

The first cog to begin turning was the generalist palliative care team. Joan's GP recognised that she was approaching the end of life and arranged advance care planning conversations. A district nurse visited regularly, reviewed her symptoms, ensured medications were available at home, and

³⁰ Abel, J. (2018). Compassionate communities and end-of-life care. *Clinical Medicine*, 18(1), 6–8.

<https://doi.org/10.7861/clinmedicine.18-1-6>

³¹ Abel, J., Kellehear, A., & Karapliagou, A. (2018). Palliative care: The new essentials. *Annals of Palliative Medicine*, 7(Suppl. 2), S3–S14. <https://doi.org/10.21037/apm.2018.03.04>

coordinated support with social care. Because her situation was identified early by her daughter and GP, crises that might otherwise have led to emergency hospital admissions were anticipated and managed.

Several months later, episodes of severe breathlessness and anxiety became harder to control. The second cog, specialist palliative care, joined the team. A consultant and specialist nurse adjusted her medication and helped the GP team develop a plan for managing distressing symptoms. They reassured Joan and Sarah that expertise was available day and night if needed. As her confidence grew, so did her determination to stay at home.

The third cog was less visible but equally important. A community development worker helped Joan and Sarah map the people already present in their lives. An inner circle emerged: Sarah, a neighbour called Alice, Joan's brother Peter, and Susan, a close friend from church. Around them sat a larger outer circle consisting of neighbours, former colleagues, members of the church congregation, and people from a local walking group with whom Joan had once volunteered.

Soon a rota appeared on Joan's refrigerator. Someone collected prescriptions. Another person walked the dog. Alice prepared extra meals and left them on the doorstep. Peter stayed overnight when Sarah needed rest. Friends visited not to provide medical care, but to share tea, conversation, memories, and silence. What had seemed like an individual burden slowly became a shared responsibility. Sarah no longer felt alone. Joan no longer felt abandoned. This compassionate community absorbed much of the practical and emotional labour that health services could never fully provide.

The fourth cog, civic action, operated in the background. Sarah's employer allowed flexible working arrangements. The local church organised volunteers and offered transport for appointments. A bereavement café, established through a compassionate community initiative, was already known to the family. Conversations about dying were not hidden away as private tragedies but understood as part of community life. The institutions that shaped everyday life supported the people doing the caring.

As autumn turned to winter, Joan weakened. One evening, after spending several hours listening to quiet music with Sarah and Alice, she fell asleep in her armchair. Her breathing gradually slowed. Sarah gave the medication that the nurses had prepared and telephoned the on-call service. The district nurse arrived shortly afterwards, checked that Joan was comfortable, and remained with the family.

Joan died at home before dawn.

The days that followed revealed why all four cogs are essential. The healthcare professionals ensured that practical arrangements were handled smoothly. Friends continued bringing meals and visiting. Sarah attended the bereavement café where she met others navigating similar losses. Her workplace maintained flexible arrangements while she adjusted to life after her mother's death. The relationships formed during Joan's illness did not disappear when she died; they carried on into bereavement.

Months later, Sarah reflected that her mother's death had been sad but not catastrophic. There had been suffering, fatigue, and grief, but there had also been support, companionship, and meaning. Looking back, she realised that no single person or service had achieved this

outcome. It was the combined movement of all four cogs, specialist care, generalist care, compassionate community, and civic support, that had made it possible. Together, they had sustained not only Joan's care, but the wellbeing of everyone around her.

What we learned from our conversations

Between June and September 2026, we met with over 30 people to learn about end-of-life care in Lincolnshire. These were not formal interviews, but informal conversations where we were able to explain our exploratory project and hear what others thought. We spoke to people from NHS community and acute services, the Lincolnshire Integrated Care Board, public health, adult social care, care home and domiciliary care providers, chaplaincy, the voluntary and community sector, faith communities, community development, and specialist palliative and dementia services.

It was common for people to refer to British cultural attitudes toward death and dying as a systemic barrier to better end of life experience. We don't talk enough about death and dying! This avoidance is not only confined to the general public. We were told that healthcare professionals frequently avoid initiating conversations about death, ReSPECT forms, and advance care planning. Multiple people described to us a pattern in which such conversations are deferred until crisis point, when a patient deteriorates rapidly, when a family presents in hospital, or when emergency services are called, rendering them less effective and more distressing for all involved. The ReSPECT document, which is intended to capture an individual's preferences for emergency treatment and end of life care, is widely seen as a clinical instrument owned by healthcare professionals rather than as a document that belongs to the individual and can be initiated by anyone. We were told of one example where a nursing home resident did not know they had a ReSPECT form because it had been completed without a meaningful conversation.

This avoidance is cultural and historical. The increasing medicalisation of death in the twentieth century, accelerated by the development of universal health care, created a social contract in which citizens effectively delegated responsibility for dying to professional services. This has produced generations of people with limited experiential knowledge of death and dying, low confidence in supporting others through the dying process, and an impoverished vocabulary for discussing it. This was illustrated by one example where a palliative care nurse told us that their siblings would not engage with conversations about their father's end of life plans.

Several participants identified dementia as presenting specific challenges. Dementia is a terminal diagnosis but is rarely treated as such in planning or practice. The timing of advance care planning is particularly fraught: if conversations are initiated too early after diagnosis, they can feel insensitive; yet if they are left too late, the person loses capacity to participate meaningfully. We were told about clinical encounters where families had never had any advance care planning conversations, because clinicians in community settings had judged the timing wrong or had avoided the conversation entirely. We learned about the closure in July 2026 of Lincolnshire's memory support service, which has created a significant gap in support for people with dementia and their families, including around advance planning and end of life preparation. We heard how hospice care is rarely available to people with dementia, owing to capacity and staffing constraints. A real concern is that people with dementia may display highly challenging behaviours, such as agitation, aggression, distress, that persist until very close to death, making community care or transfer to a care home

extremely difficult. For those individuals, the specialist dementia ward effectively becomes a substitute community by default rather than by design.

At the strategic level, we found a strong alignment between the compassionate communities framework and existing priorities. The Lincolnshire ICB's whole population health strategy identifies palliative and end of life care as one of five priority areas. There was clear interest in having the compassionate communities concept embedded in the commissioning framework and to some extent this work is already happening. We were told that a compassionate communities approach has clear synergies with Lincolnshire's public health priorities around resilient communities, vibrant neighbourhoods, and the neighbourhood health agenda. However, we heard that current ICB restructuring to create a cluster with Nottinghamshire and Derbyshire ICBs, has stalled previously active working groups on palliative care.

When speaking with people from the care home sector, we were told it is a neglected but important resource for compassionate communities work. Care homes, particularly nursing homes, support many more dying people than hospices do, but receive far less attention in policy, commissioning, and compassionate communities literature. The Gold Standard Framework, applied in a small number of nursing homes, demonstrates that high-quality palliative care practice can be embedded and sustained in care home settings. We learned of one example in Lincolnshire where the care home is the community hub, a place used for Parish Council meetings, as a Polling station and for community events. The care home workforce was identified as a largely untapped resource for community-level death literacy work. Care workers, including non-registered staff such as cleaners and kitchen staff, are frequently approached by families for guidance and support. These workers often live and are embedded in the same communities as the people they care for. We were told that by embedding death literacy education across the care home workforce, rather than restricting it to clinical staff, it would multiply the reach of compassionate communities work into community settings.

We were intrigued to hear that a previous NHS co-production group in Lincolnshire had explored the potential of 'end of life doulas' at length, arriving at strong endorsement from people with lived experience, only for the model to be dropped when brought to formal NHS governance. There is now renewed interest in the model. We know that End of Life Doulas UK has partnered with NHS bodies in three areas (Sutton and Merton; Leeds; Kingston and Richmond) with positive outcomes. However, the lack of trained doulas in Lincolnshire represents a challenge but also an opportunity.

Death cafés, informal gatherings for open conversation about death and dying, held in everyday community settings, generated enthusiasm in several meetings. The death café model has previously been explored but momentum had stalled because of governance and volunteer management processes. A wider online meeting organised by Every-One in September 2026 attracted significant interest across the health, social care and voluntary sectors, suggesting appetite for a locally organised death café programme.

Across many of our meetings and the research literature, too, a consistent observation was that compassionate communities work requires genuine community development at its core. The city of Lincoln has some excellent examples of this such as the Sincil Bank development, work with rough sleepers and people with special needs and disabilities. It seems there is both the breadth and depth of experience to develop long-term, asset-based engagement with

residents; building organisations that will outlast project funding; developing leaders from within communities; and creating physical presence in the neighbourhood. This is the experience that compassionate communities work needs to draw on.

Finally, the role of St Barnabas hospice was widely recognised both as a centre of expertise and for its work over the years that has aligned with a compassionate communities approach, including employing a community development officer. Hospices are often the co-ordinating hubs of compassionate communities, but this natural assumption is now being challenged because it reinforces that death and dying are exclusively the ‘business’ of hospices, rather than everybody’s responsibility. A compassionate city and compassionate communities should celebrate everything that hospices provide but not rely on them to lead all the time.

Overall, our conversations highlighted to us a system in which the need for compassionate communities work is widely recognised, the strategic conditions are increasingly favourable (at times seemingly inevitable), and the human and organisational ‘assets’ for doing this work are already present in Lincoln and Lincolnshire. We learned that what has been absent is a sustained, coordinating mechanism to bring everyone together around a shared framework focused on *dying as a social experience*.

Useful documents for Compassionate Communities in Lincolnshire

We identified over 50 documents specific to Lincolnshire and relevant to compassionate communities (Appendix 2).

The documents span the period 2017 to 2026 and collectively constitute the primary policy, strategic, operational, and epidemiological evidence base for understanding end of life care and therefore the conditions for compassionate communities in Lincolnshire. They encompass NHS commissioning strategies, Lincolnshire County Council and district council policy documents, Director of Public Health annual reports, hospice strategies and cross-organisational clinical guidelines, patient and carer engagement findings, workforce analyses, co-production and personalisation frameworks, patient-facing clinical tools, VCFSE infrastructure strategies, and statistical baseline data. Altogether, they provide a comprehensive and complex picture of what is known, what is planned, and where significant gaps remain.

Several themes recur consistently across the documents we collected. The most fundamental is the persistent under-identification of people approaching the end of life: multiple documents confirm that only around 0.7–0.8% of Lincolnshire’s population are on the palliative register at any one time, against a national expectation of 1–2%, and that more than 40% of people who die of conditions where palliative care would be expected are never registered at all. Late registration – often within the final four weeks of life – compounds this, limiting the time available for advance care planning, community support mobilisation, and carer preparation.

A second consistent theme is the fragility of the workforce and the inadequacy of carer support. Staff turnover in adult social care reaches 30–33%, the formal workforce faces a projected shortfall of 8,100 posts by 2040, and over 70% of Lincolnshire’s estimated 70,000+ unpaid carers report feeling unsupported and unrecognised. The documents show that community and voluntary sector support is not a discretionary supplement to formal care but already an essential component of it.

Third, the documents demonstrate a coherent and explicit strategic alignment around the ambition for people to ‘live, age and die well’ in Lincolnshire. This framing demonstrates genuine system-level endorsement of end of life care as a commissioning priority and provides the policy foundation on which a compassionate communities programme can position itself.

Finally, the documents reveal a well-developed infrastructure of voluntary, community, faith, and social enterprise organisations across Lincolnshire, already delivering elements of compassionate communities practice without the benefit of a shared framework, coordinating body, or explicit public mandate for end of life care. Collectively, the documents clearly demonstrate that the conditions for a Compassionate Lincolnshire initiative are both favourable and timely.

Organisations, programmes and initiatives in Lincolnshire

We identified over 40 websites specific to Lincolnshire and relevant to compassionate communities (Appendix 3). The list is not exhaustive.

The websites span specialist hospice and clinical services, statutory community support, voluntary and community sector organisations, carer support networks, personalisation and social prescribing programmes, spiritual and pastoral care providers, and practical community support services. They reveal both the breadth of existing provision and the gaps that a coordinated compassionate communities initiative could address.

The most directly relevant sites are those providing specialist end of life care infrastructure: the Lincolnshire EOLC hub, St Barnabas Hospice and its wellbeing and bereavement services, the Butterfly Hospice in Boston, and Marie Curie Companions. Together, these demonstrate that Lincolnshire has a well-developed specialist palliative care offer, including a publicly accessible online resource centre, volunteer-delivered bereavement support, and a hospice at home service.

A second cluster of websites reveals a sophisticated personalisation and social prescribing ecosystem already operating across Lincolnshire. The It’s All About People programme, Connect to Support Lincolnshire, How Are You Lincolnshire, and the LVET network together constitute a functioning infrastructure of community connectors, social prescribing link workers, online directories, and community development capacity. Compassionate Lincolnshire does not need to start from scratch; it first needs to embed end of life care, bereavement, and carer support explicitly within the existing provision.

The carer-focused sites, Carers First and the Lincolnshire Carers Service, affirm that the county’s 70,000+ unpaid carers are the backbone of home-based end of life care and that they are chronically under-supported, under-identified, and under-resourced. Spiritual and pastoral care, provided by the ULH Chaplaincy, Lincoln Cathedral, Lincoln Prison, the University of Lincoln Multi-Faith Chaplaincy, and the Lincolnshire Faith Council, is present but fragmented, and we found no shared framework connecting faith communities to end of life care planning.

Overall, we found lots of evidence of information and activity that a Compassionate Lincolnshire initiative is well placed to utilise, draw on and learn from. It could act as a

trusted navigator, connecting dying people, their carers, and their communities to the support that already exists, whilst making the case for what is still missing.

The importance of death education

Public health palliative care has a strong education component with death education as a central concern. Prof. Allan Kellehear, who first made the case for compassionate communities,³² argues there are nine good reasons to implement death education as part of a wider public health approach to health and well-being.³³

- (1) encouraging a normalization of death and loss;
- (2) building on, learning from, and consolidating personal and community experience;
- (3) promoting a public understanding that there is more to death and dying than palliative care or grief work;
- (4) restoring a social context to (the often frightening) problem-focused professional images of death, dying, and loss;
- (5) keeping abreast of the latest research about death, dying, and loss as informed consumers of related health services;
- (6) minimizing personal and community anxiety, fear, and hysteria;
- (7) maximizing an informed sense of hope and control—knowledge is power and encourages mastery;
- (8) combating personal and community ignorance, major sources of fear and prejudice that always hobble, narrow, even hide our full range of human choices and responses;
- (9) reducing the morbidity and mortality rates associated with, but underrecognized as associated with, death, dying, and loss.

Death education can be thought of as “the study of life – with death left in”.³⁴ It is the proactive study of mortality and dying. Death education courses have been taught in universities since the 1960s. There are now well-established university research centres from which courses are designed and run.³⁵ Such courses often focus on understanding death, dying, and bereavement through a combination of philosophy, psychology, sociology and religious studies and typically aim to promote positive attitudes towards death and reduce

³² Kellehear, A. (2005). *Compassionate cities: Public health and end-of-life care*. Routledge.
<https://doi.org/10.4324/9780203019955>

³³ Kellehear, A. (2014). Death education as a public health issue. In J. M. Stillion & T. Attig (Eds.), *Death, dying, and bereavement: Contemporary perspectives, institutions, and practices*. Springer Publishing Company. <https://doi.org/10.1891/9780826171429.0016>

³⁴ Kastenbaum, R. (2004). *On our way: The final passage through life and death*. University of California Press. p. 19.

³⁵ For example: The University of Durham <https://www.durham.ac.uk/research/institutes-and-centres/death-life-studies/> ; The University of Bath <https://www.bath.ac.uk/research-centres/centre-for-death-society/> ; The Open University <https://www.open.edu/openlearn/health-sports-psychology/open-thanatology> ; and The University of Glasgow <https://www.gla.ac.uk/research/az/endoflifestudies/>

fear and anxiety.³⁶ We can easily grasp the breadth of topics on a death education course by looking at a popular textbook³⁷ or current syllabus.³⁸

The treatment of death and dying in the English school curriculum has always been patchy, usually appearing intermittently through religious education, biology, literature, PSHE, pastoral care and responses to actual bereavements. From September 2026, revised statutory guidance requires primary schools to cover in the curriculum: “That change and loss, including bereavement, can provoke a range of feelings, that grief is a natural response to bereavement, and that everyone grieves differently.”³⁹ The statutory guidance does not extend to secondary schools and the current provision of death education in schools remains dependent on local syllabuses, individual teachers, school leadership and voluntary-sector resources. Empirical studies have repeatedly found provision reactive, inconsistent and constrained by uncertainty, limited training and fear of causing distress.⁴⁰ There are however, several specialist organisations, such as Child Bereavement UK which offer training and teaching resources for schools.⁴¹

In the private sector, some organisations have developed courses which focus on death, dying and end of life care. An end of life doula (‘death doula’) is someone who provides advocacy, companionship and non-medical support to a dying person and those who care for them. It is a role that is undertaken voluntarily or for payment. Training to be an end of life doula has been offered in the UK by Living Well Dying Well Training (LWDW)⁴² since 2010 and a separate membership association, End of Life Doula UK (EoLDUK)⁴³, was established in 2018. The Foundation course offered by LWDW covers four topics: Understanding the dying phase; Understanding the effects of death on those who are caring; Engaging in the doula role, and Choices and requirements at the time of death and dying. A two-year diploma course expands on this foundational syllabus.

A number of frameworks of competencies and skills exist for training in end-of-life care in a professional and community context, too.⁴⁴ The documents we found, spanning from 2013 to

³⁶ Romão, M. E., Belli, G., Jumayeva, S., Visonà, S. D., Woodthorpe, K., Setti, I., & Barelo, S. (2025). Death education in practice: A scoping review of interventions, strategies, and psychosocial impact. *OMEGA: Journal of Death and Dying*. <https://doi.org/10.1177/00302228251338643>

³⁷ Kastenbaum & Moreman (2024). https://www.google.co.uk/books/edition/Death_Society_and_Human_Experience/eVYIEQAAQBAJ?hl=en&gbpv=0

³⁸ For example: https://css2.open.ac.uk/outis/descs/mc_courses/K220.htm and <https://www.gla.ac.uk/postgraduate/taught/endoflifestudies/>

³⁹ Department for Education. (2025). *Relationships education, relationships and sex education and health education guidance: For introduction 1 September 2026*. UK Government. https://assets.publishing.service.gov.uk/media/6970e7e67e827090d02d42e0/Relationships_education_relationships_and_sex_education_RSE_and_health_education_for_intro_1_September_2026.pdf

⁴⁰ Dawson, L., Hare, R., Selman, L., Boseley, T., & Penny, A. (2023). “The one thing guaranteed in life and yet they won’t teach you about it”: The case for mandatory grief education in UK schools. *Bereavement*, 2. <https://doi.org/10.54210/bj.2023.1082>

⁴¹ <https://www.childbereavementuk.org/Listing/Category/education-training>

⁴² <https://lwdwtraining.uk/>

⁴³ <https://eol-doula.uk/>

⁴⁴ Gamondi, C., Larkin, P., & Payne, S. (2013). Core competencies in palliative care: An EAPC White Paper on palliative care education, Part 2. *European Journal of Palliative Care*, 20(3), 140–145. https://www.sicp.it/wp-content/uploads/2018/12/6_EJPC203Gamondi_part2_0.PDF

Skills for Care, & Skills for Health. (2014). *Common core principles and competences for social care and health workers working with adults at the end of life* (2nd ed.).

2026, trace a consistent direction of travel: from the recognition that dying is a social and relational – not merely clinical – process, towards the formal embedding of community engagement as a professional obligation and a workforce competence at every tier of the health and care system.

When looked at together, we found that the foundational conceptual architecture was established by the EAPC White Paper (Gamondi et al., 2013). It articulated ten competencies grounded in the WHO definition of palliative care as a holistic approach encompassing physical, psychological, social, and spiritual dimensions. Its explicit recognition of volunteers as essential contributors to supportive care, and its argument that palliative care principles should be integrated into every discipline's core curriculum rather than ring-fenced within specialist services, influenced the direction of all subsequent English national policy. The *Common Core Principles* (Skills for Care & Skills for Health, 2014) appears to have translated this European framework into the English national context. It extended the target audience beyond the registered clinical and social care workforce to include community workers, faith leaders, housing workers, and education workers. In doing so, it legitimised the participation and training of community members in end of life care.

The HEE *Core Skills Education and Training Framework* (2017) built directly on the 2014 principles, introducing 14 subjects and three workforce tiers, and for the first time positioned the general public and volunteers as explicit recipients of national end of life care training through its learning outcomes on community skills development. It references Ambition 6 ('Each community is prepared to help') as its policy mandate and we might interpret this as a commitment to the development of compassionate communities as a workforce and community development goal.

For the specialist workforce, the NHSE *Advanced Practice Framework* (2023) establishes that compassionate communities work is not just compatible with advanced palliative care practice but is a formal professional requirement: Capability CP4.10 obliges advanced practitioners to promote dying as a social process and to initiate community engagement interventions, while Capability CP1.10 requires effective partnership with third sector and volunteer organisations as 'an essential component' of end of life care.

The January 2026 Skills for Health consultation document, *End of Life Care Core Capabilities Framework* includes a 'Tier 1' role, which refers to "Those that require general end of life care awareness, focusing on a community development, asset-based approach to care, which is a grassroots approach that builds on a community's existing strengths and resources, rather than focusing on deficits and problems." Its Capability 5: 'Developing end of life care skills within the community', spans all three tiers and, at Tier 3, constitutes the

<https://www.skillsforcare.org.uk/resources/documents/Developing-your-workforce/Care-topics/End-of-life-care/common-core-competences-and-principles-for-end-of-life-care.pdf>

Health Education England, Skills for Health, & Skills for Care. (2017). *End of life care core skills education and training framework*. Health Education England.

<https://www.skillsforhealth.org.uk/content/uploads/2021/01/EoLC-Core-Skills-Training-Framework.pdf>
NHS England Centre for Advancing Practice. (2023). *Palliative and end-of-life care advanced practice area-specific capability and curriculum framework*. NHS England. <https://advanced-practice.hee.nhs.uk/wp-content/uploads/sites/28/2025/01/Palliative-and-end-of-life-care-advanced-practice-area-specific-capability-and-curriculum-framework-NHSE.pdf>

Skills for Care, & Skills for Health. (2026, January). *End of life care core capabilities framework: Draft for consultation, 8 January 2026*. <https://www.skillsforhealth.org.uk/article/consultations-end-of-life-care-and-frailty-frameworks/> The PDF consultation document is no longer available online.

ability to ‘influence and strengthen the community to provide support for people approaching the end of life’ as a specialist professional competence. The Framework is not a vehicle to deliver death literacy – in some respects it goes beyond what the DLI-R measures – but it is reassuring to find a proposed national framework recognise the central role of community development as a method of developing end of life care capabilities among the public and specifically among people with terminal illness and their carers. We look forward to the final publication of the Framework.

Altogether, these frameworks make a clear argument that the expectation for community education and engagement is not an add-on to palliative care but is embedded at every level of its professional framework, from members of the public to consultant practitioners. A key objective for Compassionate Lincolnshire is not to justify this approach but to help implement it, guided by the Tier 1 capabilities of the 2026 framework for community volunteers. Doing so would align Compassionate Lincolnshire with a well-established, nationally mandated framework that already exists and could act as the operational mechanism through which Ambition 6 and the community-facing tiers of the 2026 capabilities framework are delivered locally.

Case studies

There are now many published accounts of compassionate cities and compassionate community initiatives.⁴⁵ As we were writing this report, a downloadable open access book (Hodges & Patel, 2026) was published to evidence the methods, achievements and challenges of twenty initiatives from around the world. Below, we have selected five ‘stories’ from the book to illustrate what they can look like. Read together, they show that there is no single model of a compassionate community. What they share is the conviction that death, dying, loss, and caregiving are social experiences that belong to communities as much as to healthcare systems, and that the conditions under which people live and die well are created in ordinary places by ordinary people given the knowledge, confidence, and permission to act. The book is very accessible and provides much more detail than we have been able to encapsulate here.

1. Compassionate Birmingham

Birmingham is England’s second largest city, with a population of 1.15 million, significant ethnic diversity, and levels of multiple deprivation that place 60 per cent of its population in the lowest three deciles nationally. It was endorsed as the UK’s first Compassionate City by Compassionate Communities UK in February 2022, a designation awarded not to a perfected model but to a place demonstrating significant progress and a credible forward plan.

⁴⁵ Barry, V., & Patel, M. (2013). *An overview of compassionate communities in England*. London. Murray Hall Community Trust. https://conversationsforlife.co.uk/wp-content/uploads/2013/08/CC_Report_Final_July_2013.pdf

Wegleitner, K., Heimerl, K., & Kellehear, A. (Eds). (2015). *Compassionate Communities: Case studies from Britain and Europe*. Routledge. <https://doi.org/10.4324/9781315735801>

Quintiens, B. et al., (2022). Area-Based Compassionate Communities: A systematic integrative review of existing initiatives worldwide. *Palliative Medicine*, 36(3), 422–442. <https://doi.org/10.1177/02692163211067363>

Hodges, E., & Patel, M. (2026). *Compassionate Communities in Action: Global Stories of Care, Loss and Connection*. Routledge. <https://doi.org/10.4324/9781003621348>

The origins of compassionate communities work in Birmingham lie in 2009, when Murray Hall Community Trust and Birmingham St Mary's Hospice participated in West Midlands Strategic Health Authority pilot projects informed by Kellehear's framework. These early efforts struggled to gain institutional traction until the COVID-19 pandemic created the necessary political and organisational will. The pandemic's direct impact on bereavement and the wider recognition that 95 per cent of the time spent by seriously ill and grieving people is spent outside clinical settings prompted Birmingham City Council's Public Health Department to take a lead role, in partnership with Compassionate Communities UK. The Public Health department was identified as the most appropriate institutional home because it operates across the whole city, is not a service provider, and is philosophically aligned with Ottawa Charter principles.

The programme works across three levels: grassroots community activity, organisational and service alignment, and city government and policy. Activities have included: the annual A Matter of Life and Death (AMOLAD) festival run by Brum YODO (you only die once)⁴⁶, an arts-led event creating space for public conversation about death and dying; a bereavement awareness programme reaching 122 staff and 46 community members across five constituencies, LGBTQ+-specific end-of-life planning workshops; a grief and bereavement training programme for prison inmates co-designed with Birmingham Hospice, and a pilot use of the Death Literacy Index. A city-wide approach to bereavement and a befriending programme scoping exercise were in development at the time of writing. Compassionate Birmingham has also been integrated into the city's emerging Ageing Well Strategy, with compassion named as one of three guiding principles alongside independence and choice.

The principal challenges have been sustaining momentum across personnel changes, managing the complexity of a hyper-diverse city of 69 wards and over 30 primary ethnic groups, and ensuring that activities reach underrepresented communities rather than defaulting to those already engaged with health services. The DLI survey results, whilst achieving statistical significance, were dominated by White women and did not reflect Birmingham's diversity, pointing to the need for more granular community development work. The Fairer Futures programme, working with 12 community centres in the South Asian community, and the city-wide bereavement film project represent efforts to address these gaps. Birmingham's experience underlines that working at city scale brings policy leverage but also structural complexity that can impede the grassroots ownership on which sustained cultural change depends.

2. Brereton, Staffordshire

Brereton and Ravenhill is a former coal-mining village in Staffordshire with a population of approximately 7,000. In September 2021 it became the first area in the UK to be endorsed as a Compassionate Community, a recognition that reflected both its pre-pandemic community infrastructure and its extraordinary collective response to the crisis of 2020. The account given in the book is beautifully written in the first person by Sue Merriman, who is the community development worker employed by Brereton Million, the organisation established with a £1 million National Lottery Big Local award in 2015 to enable residents to invest in their own community over ten years.

⁴⁶ <https://brumyodo.org.uk/>

Brereton Million was established with a board of 12 local volunteers charged with distributing resources according to community priorities identified through extensive door-knocking and consultation. The early investment priorities: a rebuilt children's play park; a community hub; the Brereton Grows food-growing initiative, and the Vysions youth programme, all reflected a community spirit rooted in the village's mining history. When the pandemic arrived in March 2020, this pre-existing infrastructure and the trust relationships it embodied enabled rapid mobilisation: volunteers knocked on all 3,000 households in the village, identified isolated and vulnerable residents, established a phone buddy system, coordinated food distribution, organised handmade PPE, and sat with people who were dying when formal care was unavailable. Over 150 residents volunteered at the height of the crisis.

What distinguishes Brereton from most other compassionate community initiatives is the degree of authentic resident leadership. The work was not initiated by a healthcare organisation or statutory body and has not been medicalised. Death literacy emerged organically from the experience of COVID rather than from a public health framework, and a subsequent DLI survey showed Brereton's scores to be significantly above the UK average across all subscales, with particular strength in experiential and community knowledge – findings consistent with the high levels of social connectedness that characterise the village. The endorsement process in 2021 gave the community a framework for understanding what it had been doing and a platform for what needed to be strengthened, leading to involvement in CCUK's Pallilearn programme⁴⁷ and the Japanese Lessons of Life⁴⁸ initiative for young people.

The key lesson from Brereton is that organised and well-resourced community development led by trusted local people makes a difference that externally delivered services cannot replicate. The community hub, the carnival, the allotment gardens, and the youth programme all function as infrastructure for the deeper compassionate work. The principal vulnerability is the dependence on a single community development worker; as the Big Local funding ends, the challenge is to secure the financial sustainability of Vysions,⁴⁹ the new charity incorporating all Brereton Million activities, and to ensure that the training and support structures necessary to sustain volunteers without burn-out are in place.

3. Compassionate Inverclyde, Scotland

Inverclyde is a mixed urban and coastal community of approximately 80,000 people in West Central Scotland, characterised by considerable scenic beauty alongside high levels of poverty, unemployment, disability, and trauma. Life expectancy is below the Scottish average, though the population is ageing rapidly. The Compassionate Inverclyde initiative⁵⁰ was founded in 2016 by the Director of Care at Ardgowan Hospice, who was inspired by Kellehear's framework and who undertook a Florence Nightingale Foundation scholarship to learn from compassionate communities in England, Australia, and the USA before establishing a programme board co-chaired by a local councillor and the Chief Officer of Inverclyde Health and Social Care Partnership.

The initiative is described by its founders as a social movement rather than a programme, and its ethos, 'Ordinary people making a difference together', reflects a consistent commitment to

⁴⁷ <https://palliativecaresa.org.au/pallilearn/>

⁴⁸ https://ehospice.com/uk_posts/lessons-of-life/

⁴⁹ <https://www.vysions.org.uk/>

⁵⁰ <https://compassionateinverclyde.org/>

bottom-up community ownership. A diverse board including citizens, healthcare, social care, schools, police, prison service, and local business has governed the work, and organic growth through social media, storytelling, and community events has been central to the approach. Key activities include the No One Dies Alone (NODA)⁵¹ companion scheme, in which trained volunteers sit with people in their final hours in hospital and care homes; the Back Home Boxes⁵² programme, providing practical supplies to adults of all ages returning from hospital alone (5,236 boxes distributed to date); the High 5 well-being programme for adults, prisoners, and school pupils; a bereavement café that evolved into a weekly community friendship hub; and a Kindness Award scheme under which 14 Inverclyde organisations have achieved Bereavement Charter Mark status.

Inverclyde is notable for the strength of its evaluation evidence. An independent formative evaluation in 2018 identified significant individual, relational, and community outcomes. A Social Return on Investment analysis in 2023 estimated at least a 3:1 return in terms of well-being, resilience, and social capital, as well as costs avoided by statutory services, a finding the authors note is almost certainly an underestimate. The NODA programme alone has directly benefited over 200 patients, and the Back Home Boxes scheme has contributed to Inverclyde's strong performance on hospital discharge metrics. The breadth and reach of the programme across multiple population groups and the sustained involvement of over 90 volunteers speaks to the depth of cultural embedding achieved over nearly a decade.

In 2024, Compassionate Inverclyde became an independent Scottish Charitable Incorporated Organisation, a milestone that coincided with the publication of a new HSCP strategic plan framing Inverclyde itself as a compassionate community, the most visible sign of the initiative's influence on the institutional culture of health and social care governance in the area. The new SCIO's five strategic objectives, including promoting compassionate citizenship, fostering bereavement-friendly organisations, and building financial sustainability, reflect lessons hard-won from the experience of hosting by a hospice. The Inverclyde case remains one of the most comprehensively documented examples of a compassionate community initiative achieving measurable social value at modest cost.

4. Mid & East Antrim, Northern Ireland – Agewell Partnership

The Mid & East Antrim Agewell Partnership is a small charity based in Ballymena, Northern Ireland, that supports older people across the Mid and East Antrim area through asset-based community development.⁵³ The region is predominantly rural, shaped by the legacy of the Troubles, and characterised by social divides that run along religious and cultural lines. It is this context – communities for whom death has been both ever-present and surrounded by silence – that gives the Agewell initiatives their particular significance. The chapter documents three distinct but related projects: *Mars Bar and Apple Sandwiches and Other Stories*, Northern Ireland's first Funeral Festival, and the *Dying Art of Conversations* programme.

Mars Bar and Apple Sandwiches originated from an offhand remark at a community group discussion about funeral traditions – the observation that you could tell a Presbyterian funeral by the sandwich – that sparked a wave of shared memory and led to a community-authored book of stories about death, funerals, and grief across cultural, religious, and ethnic

⁵¹ <https://www.nodaa.org.uk/>

⁵² https://www.goodlifedeathgrief.org.uk/toolkit_inverclyde_back_home_box/

⁵³ <https://meaap.co.uk/>

backgrounds. Working in partnership with the Mid & East Antrim Inter Ethnic Forum and supported by the Borough Council's Community Relations Fund, the project collected contributions ranging from traditional Irish Catholic wake customs to Hindu cremation ceremonies to Polish Catholic practices. The recurring discovery that cultures share more than they assume – covering mirrors at death, for example, is a practice found in Presbyterian, Jewish, and Polish Catholic traditions alike – served a specific purpose in a region where sectarian division has historically foreclosed exactly this kind of cross-community recognition.

The Funeral Festival of 2022, Northern Ireland's first, assembled professionals from across the end-of-life sector – funeral directors, florists, solicitors, humanists, palliative care nurses, and crematorium staff – in a wedding-fair atmosphere designed to normalise rather than solemnise the topic. Attendees reported empowerment, a first occasion for many to touch a coffin, and a catalyst for previously postponed legal and funeral planning.

The *Dying Art of Conversations* programme, funded by the Arts Council of Northern Ireland, engaged six community groups and care homes with professional artists working in music, movement, and visual art over an extended period, using creative practice to open conversations that formal methods had been unable to reach. For example, a previously non-verbal and withdrawn care home resident who had once been a secondary school art teacher began to express herself through painting; another participant completed a will for the first time after decades of avoidance.

The Agewell case illustrates several principles of particular relevance to community health initiatives in divided or fragmented societies. First, culture and food, seemingly ordinary entry points, can reach parts of a community inaccessible to formal health promotion. Second, the arts offer a non-threatening route to conversations that purely informational approaches cannot facilitate. Third, in contexts of sectarian or cultural division, the discovery of shared human practices around death offers a form of community building that transcends political difference. The approach is asset-based, co-produced, and deliberately low-cost, relying on the skills of professional artists and the lived experience of older community members rather than clinical expertise.

5. Compassionate Communities Up the East Coast, Suffolk

Established in 2020 and led by St Elizabeth Hospice in Ipswich, the East Coast initiative operates across Suffolk, a county of approximately 400,000 people characterised by rural isolation, one of the highest proportions of older people in the UK, significant socio-economic deprivation, and limited public transport links. The initiative was founded with the explicit recognition that clinical palliative care services alone cannot reach the 95 per cent of time that seriously ill and grieving people spend outside healthcare settings, and that cultural confidence in supporting one another through death and loss requires deliberate community development over time.

The centrepiece of the work has been the *Compassionate Conversations* programme,⁵⁴ a two-hour workshop designed to empower lay people to listen and be present with those affected by death – to dispel the panic that leads people to cross the street or look at their phones, and to replace it with the simple confidence to sit in silence, ask gentle questions, and offer

⁵⁴ <https://www.stelizabethhospice.org.uk/supporting-you/in-your-community/compassionate-conversations/>

companionship. Since 2021, over 112 sessions have been delivered to 2,090 participants across prisons, cafés, schools, creative hubs, community centres, and sporting clubs. The programme has been complemented by an expanding portfolio of activities: a *Compassionate Workplaces* scheme that has engaged over 70 workplaces and led to the introduction of bereavement policies; a ‘Before I Die’ wall in public space; over 70 awareness posters in everyday settings with QR codes linking to bereavement support; Bereavement Bookcases installed in 14 Suffolk libraries generating 3,225 loans in 15 months; six bereavement benches in Felixstowe and Woodbridge; a partnership with Snape Maltings and The Red House leading to a commissioned theatre tour and collaborative music projects; a No Barriers Here programme using visual art to support advance care planning with people with learning disabilities; and the Larch Project, pairing hospice patients with local students to co-create intergenerational tributes.

The appointment of two Community Connectors funded by the National Lottery, dedicated to building relationships with underrepresented communities, has generated over 250 conversations and led to LGBTQ+-specific hospice work, tours for people with learning disabilities, Romanian community engagement, and bespoke sessions for minority ethnic workplaces. The initiative explicitly holds the tension between measurable outcomes – sessions delivered, participants reached, organisations engaged – and the less quantifiable cultural change that is the work’s ultimate aim. Its authors are candid that there is no set formula, that community development must evolve organically, and that the work is a lifelong process without a specific endpoint.

The Suffolk case is notable for several reasons in the context of other UK examples. It demonstrates how a hospice can reorient its community-facing work away from a service delivery model without losing its clinical anchor, using a range of creative and public-space interventions to build death literacy at population level. Its rural and deprived context distinguishes it from the urban examples and raises distinct questions about transport, geographic isolation, and the role of village and small-town infrastructure. The integration of the compassionate communities lead and the clinical palliative care team within the same management structure – achieved partway through the initiative – has enabled shared learning and a more coherent relationship between community development and direct care.

Lessons for Lincolnshire

The case studies provide a useful picture of what compassionate communities work looks like in practice. This is what they tell us:

Invest in skilled, embedded community development leadership. Every successful initiative depends on a trusted, relationally skilled individual with sufficient time and institutional backing to build the networks on which everything else rests. This typically takes years rather than months. The departure of key individuals is the single most commonly cited cause of disruption across the case studies. Succession planning and adequate support structures for community development workers and volunteers should be built into the design of any initiative from the outset rather than addressed reactively.

Begin with what already exists. The most effective initiatives start by mapping existing community assets – groups, spaces, trusted individuals, and informal networks – and connecting them rather than creating parallel structures. The conclusion to the book identifies social capital as the primary common ingredient across all twenty cases. A collaborative audit

of existing voluntary sector, faith, and community organisations in Lincolnshire would be a more productive starting point than importing a model designed for a different context.

Calibrate scale to local geography and social density. The comparative evidence across the case studies consistently shows that compassionate communities work generates more measurable impact at village or neighbourhood scale, where social trust is likely to be more dense and a shared hub can anchor activity. Lincolnshire's dispersed rural population and market town structure may be better suited to a network of locally embedded initiatives connected through a light coordinating infrastructure than to a single county-wide programme.

Manage the relationship between organisational leadership and community ownership carefully. Where health or hospice organisations initiate and control the work, there is a consistent risk of reproducing a service-delivery model rather than enabling genuine community development. Community members and local organisations should shape priorities, and accountability should run towards communities as well as towards lead organisations and funders.

Use the Death Literacy Index as a planning and development tool. The UK case studies demonstrate that the DLI functions practically as a community development instrument – prompting local conversation, identifying strengths and gaps, and providing a basis for measuring change over time – and not merely as a research instrument.

Deploy arts, creative events, and schools as primary vehicles for reach. Arts, culture, and festivals are a common ingredient across nearly all cases, and the evidence demonstrates that accessible creative formats reach people who will not engage through formal health channels or consultations. Schools are identified in the Compassionate City Charter as a key site of action and represent an underused entry point.

Address sustainability at the design stage. Short-term project funding is the most consistently cited structural problem across the case studies. The core coordination function needs an identified route to sustainability from the outset of any Lincolnshire initiative, not as an afterthought when initial funding approaches its end.

Finally... recommended reading

If you are not yet persuaded by this report, then the next document to read is:

Sallnow et al. (2022) Report of the Lancet Commission on the Value of Death: Bringing death back into life. *The Lancet*, 399(10327), 837–884. [https://doi.org/10.1016/S0140-6736\(21\)02314-X](https://doi.org/10.1016/S0140-6736(21)02314-X)

During our research, we have gathered over 400 relevant books, articles, chapters, reports, strategy and policy documents. Below, we have selected three books for stakeholders in Lincolnshire to understand the ideas and practices relating to compassionate communities and death literacy. We encourage you to read and discuss them with your friends and colleagues!

A compelling collection of writing by two leading academic authors:

Abel, J., & Kellehear, A. (Eds). (2026). *Well-Being at the End of Life: Reimagining Palliative Care*. Columbia University Press. <https://cup.columbia.edu/book/well-being-at-the-end-of-life/9780231216289/>

Accessible, poignant and useful case studies:

Hodges, E., & Patel, M. (2026). *Compassionate Communities in Action: Global Stories of Care, Loss and Connection*. Routledge. <https://doi.org/10.4324/9781003621348>

Foundational text:

Kellehear, A. (2005). *Compassionate Cities*. Routledge. <https://doi.org/10.4324/9780203019955>

Appendices

There are separate accompanying documents to this report:

Appendix 1: The Death Literacy Index

Appendix 2: Relevant documents

Appendix 3: Relevant websites

Appendix 4: The Compassionate City Charter