QUEEN'S UNIVERSITY BELFAST

COMPASSIONATE COMMUNITIES POSITION PAPER

Fostering Compassionate Communities: A Call to Transform Caregiving, Dying, Death and Grieving on the Island of Ireland

Authors: Lisa Graham-Wisener,
Stephanie Crawford & Ashleen Crowe

AIIHPC
The All Ireland Institute of
Hospice and Palliative Care

Irish Hospice Foundation

Foyle Hospice
Together we care

HSC Public Health Agency

An Roinn Gnóthaí Eachtracha
Department of Foreign Affairs

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EXECUTIVE SUMMARY

Across the island of Ireland, the role of caring for people through serious illness, dying, death and grief was once widely recognised as being centred in the community. However, as palliative and end-of-life care services have advanced to make significant improvements in quality of life for individuals with serious illness and their families, society has come to view responsibility for death and dying as primarily that of healthcare professionals. This shift has led to communities feeling less confident, knowledgeable, and prepared to provide compassionate support around end-of-life.

This comes at a time when the death rate is expected to more than double across the island of Ireland in the next twenty years, coupled with an increase in the number of people dying at home [1, 2]. Many people with serious illness and their families already lack the support they need, and this gap is likely to widen in future. To achieve the highest quality and continuity of care, we argue that entire communities should be empowered to take the lead in caring for people around the end-of-life, supported by our specialist and generalist palliative care services and wider civic society. To this end, we believe that a compassionate communities approach is urgently needed to transform how we experience life and death on the island of Ireland.

This position paper proposes recommendations for supporting the development of a compassionate communities approach to caregiving, dying, death and grieving on the island of Ireland. It has been developed by Dr Lisa Graham-Wisener, Dr Ashleen Crowe and Stephanie Crawford from the School of Psychology at Queen's University Belfast. Findings in the position paper were informed by the *Inaugural Compassionate Communities in Palliative and End of Life Care Conference, Newry*, 9th September 2024 (see methods section below). This work was funded through the Shared Island Civic Society Fund from the Department of Foreign Affairs Ireland and Northern Ireland Public Health Agency, with partnership working from the All Ireland Institute for Hospice and Palliative Care, Foyle Hospice, and the Irish Hospice Foundation.

The position paper begins by outlining what the compassionate communities movement is, with a discussion of why a compassionate communities approach is needed on the island of Ireland and how this supports national policies in health and social care. This is followed by an overview of progress to date in developing community responses to caregiving, dying, death and grieving on the island of Ireland, followed by key recommendations.

The report details that:

Compassionate communities empower people to support one another through serious illness, dying, death, and grief, recognising these as shared human experiences rather than solely the responsibility of health and social care. Compassionate communities complement, rather than replace, formal services by fostering local networks of care and compassion. The compassionate communities movement also recognises that **death is everyone's business** and advocates for **wider systemic change** to ensure that individuals facing the challenges associated with serious illness encounter compassion in all aspects of their lives, including in schools, workplaces, and trade unions.

A compassionate communities approach is **highly relevant to the changing demographic profile** of our population on the island of Ireland and may contribute to addressing the particular challenges we currently experience around end-of-life, including **reducing the burden on our overstretched health and social care services**. This approach complements efforts to promote **integrated care**—a key principle in delivering seamless, person-centred support that spans community and professional services. Fostering compassionate communities across the island of Ireland **aligns to North/South national policies**, such as the new National Adult Palliative Care Policy (2024) in Ireland and both evolving Programmes for Government which place an emphasis on integrated care and community-based support. Fostering compassionate communities also presents significant **opportunities for cross-border cooperation.**

The compassionate communities model is **underdeveloped** across the island of Ireland, although there is **considerable cross-sector interest** in its advancement. The key challenges and opportunities for fostering compassionate communities are outlined below.

Table 1: Summarised key findings of conference including challenges and opportunities

KEY FINDINGS	CHALLENGES	OPPORTUNITIES
Compassionate communities initiatives need to be recognised as creating the environment for meaningful education, social awareness raising and open dialogue.	There is a need to dispel the notion that death should be the responsibility of healthcare providers. Caregiving, dying, death and grief are everyone's business. Simply informing people about matters relating to death, dying, or grief is not enough; compassionate communities empower individuals to act.	Compassionate communities provide the infrastructure that fosters conversations about death, raises social awareness, and creates supportive environments that empower action. Compassionate communities increase death literacy - the knowledge and skills people need to understand, access, and make informed decisions about end-of-life care. Using the arts to facilitate discussions of emotive topics is valuable and helps develop a compassionate culture.
On the island of Ireland, we must recognise, support and sustain initiatives that are driven by the community.	While service-led compassionate communities initiatives are the norm, community-driven, bottom-up approaches are more effective in fostering long-term sustainability and scalability. Many individuals may not recognise that their actions align with the compassionate communities movement —these initiatives must be identified and celebrated.	People with lived experience of caregiving, dying, death, and grief are uniquely positioned to identify unmet needs—we must empower people within our communities to recognise the significant value their lived experience can bring. Evidence shows community-driven initiatives are being delivered across our island—we must ensure the right environment for their continued growth. Building bridges between formal healthcare systems and community initiatives strengthens the capacity of groups and develops continuity of compassionate care.
A considered community development approach is essential, to ensure local voices and needs are prioritised and sustainable change is achieved.	It must be recognised that no single 'best example' exists for a compassionate communities initiative—communities differ in their assets, such as people and organisations, and also in what they lack. Organisations often struggle to hear the voice of the community when they do not know how to engage. If initiatives are not community-driven, organisations must engage at the right level and prioritise community voices. Unsettled times may reduce mental commitment to compassionate communities, and those willing to engage face barriers such as resource limits, inadequate support for complex care needs, and care system complexities.	Communities across the island of Ireland possess valuable strengths that we can leverage to develop compassionate community initiatives. Communities can develop initiatives by recognising unmet needs. To support this, we must amplify local community voices, particularly those with lived experience of caregiving, dying, death, and grief. Ensuring meaningful and sustained community engagement is essential to fostering compassionate communities that lead to real, lasting change across our island

KEY FINDINGS	CHALLENGES	OPPORTUNITIES
Inspiration and practical guidance are necessary to mobilise existing communities on the island of Ireland to develop compassionate initiatives.	Communities can lack both inspiration and practical guidance on how to begin building their own compassionate communities initiatives.	Communities can drive change themselves—there is untapped compassion across our island and a wealth of community assets. We must highlight that ordinary people can make a difference together and share examples of grassroots compassionate community initiatives. There is significant learning to be mobilised from individuals and organisations identified throughout this position paper, and many others, who have developed and delivered compassionate community initiatives.
Engagement from civic society across the island of Ireland is needed, to embed policies and support around caregiving, dying, death and grief within all our key institutions.	Civic society must engage beyond the context of health and social care. This is critical to ensuring compassionate support is available to people affected by serious illness in all aspects of their lives. We must recognise how interactions between individuals, communities, and their broader social environments influence care and support for those facing serious illness, dying, death, or grief.	To date Derry-Londonderry is the only city on the island of Ireland to have developed a Compassionate Cities Charter, offering an opportunity for local councils North and South to lead in prioritising compassionate support for caregiving, dying, death and grief in all key institutions. The Compassionate Civic Charter and the Bern Declaration 2024 provide a systematic approach to engage all sectors of society. There is opportunity for closer collaboration between government departments to support the expansion of programmes which have started in libraries and schools (Compassionate School Communities) and to look for other opportunities for partnership working.
Strategic leadership and investment is essential to foster compassionate communities across the island of Ireland.	Currently, no organisation has the resource to support a compassionate communities network across the island of Ireland or to provide vital strategic leadership. Many existing compassionate communities initiatives across the island face significant challenges with either a complete lack of, or short-term funding, which limits their sustainability and potential reach.	The Northern Ireland Regional Palliative Care in Partnership Programme includes a priority to develop a new public health approach to palliative and end-of-life care, and the new National Adult Palliative Care Policy (2024) in Ireland explicitly references compassionate communities. Investing in an organisation to provide strategic leadership for a compassionate communities approach is also in line with wider health policies and the evolving Programmes for Government. There is political goodwill for cross border co-operation within healthcare and public health, with significant opportunity to develop compassionate infrastructure while thinking in cross-border terms. Though compassionate communities initiatives have evidenced impact without financial backing, provision of funding to support the initiation, maintenance and evaluation of grass-roots initiatives can help the growth of a compassionate communities culture across our island.

Recommendations:

Caregiving, dying, death and grieving should not be the responsibility of health and society care. As such, it is our position that to deliver on the below recommendations, a clear mandate for fostering compassionate communities is needed from local government both North and South, with the recommendations translated into specific actions and delivered through relevant government departments.

The below recommendations are grounded in the principle that people with lived experience and communities themselves must be at the heart of delivering on all initiatives.

1. **Advocate for the adoption and implementation of this paper's recommendations by engaging with local government, government departments, councils and civic leaders**
2. **Support/establish an organisation with secured funding for at least five years to provide strategic leadership and act as a knowledge broker for compassionate communities across the island of Ireland**
3. **Deliver public awareness campaigns around the concept and benefits of compassionate communities, linked to providing recognition and reward to existing initiatives**
4. **Commission and complete an asset-mapping exercise to identify compassionate communities initiatives and community groups with potential to deliver initiatives across the island of Ireland. The results should be published in a publicly accessible online map and updated every six months**
5. **Facilitate engagement workshops in communities across the island of Ireland, to identify local need and establish partnership working between communities and health and social care.**
6. **Provide seed funding and mentorship for community groups to work in partnership with health and social care, to develop, deliver and evaluate impact of localised compassionate communities initiatives**
7. **Support the development of compassionate communities of practice, to share and to mobilise learning from existing compassionate communities initiatives**
8. **Establish steering groups for the development and delivery of compassionate civic charters in council areas both North/South**
9. **Commission research to support a 'roadmap' for fostering compassionate communities across the island of Ireland, focused on understanding local need, understanding what has worked for whom, where, and in what circumstances, and embedding best practice internationally**

We do not present this position paper as a definitive guide to what will be needed in the years to come to develop compassionate communities across our island. Rather, we hope this paper will serve to increase engagement in the need for compassionate communities and outline the critical steps which need to be taken at this point in time to support the development of a more compassionate approach to caregiving, dying, death and grieving.

Report structure

Methods: Brief summary of the sources of data that have been used to reach the positions presented in this paper.

Context: Overview of what makes a compassionate community and the relevance of compassionate communities to the island of Ireland.

Key findings: Synthesis of the key findings from the conference and progress to date in fostering a compassionate communities approach across the island of Ireland, including both challenges and opportunities.

Conclusions and Recommendations: Summary of the position paper and recommendations for fostering compassionate communities across the island of Ireland.

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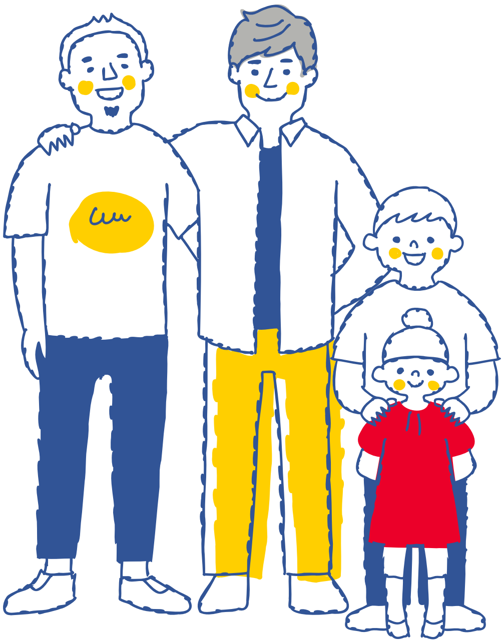


METHODS

This position paper is based on outcomes from the *Inaugural Compassionate Communities in Palliative and End of Life Care Conference* (9th September 2024, Canal Court Hotel Newry) alongside expert stakeholder consultation. There were 120 conference attendees representing various sectors, including religious, education, voluntary, health care and local authority, as well as members of the public and individuals with lived experience of caregiving, dying, death and grief. Participants came from across the island of Ireland.

The following sources of data have been used to reach the positions presented in this paper.

I) On conference registration, conference attendees were asked to share details of any projects they are involved in which aim to support people with life-limiting conditions or people dealing with dying, death, and grief in the community

II) Researchers attended the conference and made observations on critical progress of compassionate communities to date. This included considerations of what is going well, what is not going well, what are the gaps, and what is needed.

III) A roundtable discussion was conducted at the conference informed by the nominal group technique. The roundtable discussion was open to all registered participants of the conference and involved a roundtable discussion across 11 tables. At the roundtable discussion two questions were posed by a facilitator. These questions were "What types of initiatives do you think should be prioritised to develop a compassionate response to caregiving, dying, death and grieving on the island of Ireland?", and "How do you think communities could be supported to develop initiatives around caregiving, dying, death and grieving?". Through a number of stages, individuals provided a response to each question and then responses were prioritised by the table.

IV) Expert stakeholders (n=17), with lived and professional experience, were consulted via four workshops during November 2024 to ensure completeness of the report and refinement of recommendations. This included individuals from the AIIHPC Voices4Care, from across the specialist palliative care sector, from community groups and organisations, and from policy.

COMPASSIONATE COMMUNITIES

The *Compassionate Communities* approach emphasises that caregiving, dying, death, and grief are shared responsibilities of the whole community. It champions a social model of care, encouraging communities to come together in supporting those facing the challenges associated with serious illness. This approach complements rather than replaces formal health and social care services, ensuring continuity and quality of care by empowering individuals and groups to provide practical, emotional, social, and spiritual support. By normalising what are universal experiences, compassionate communities challenge the perception of death as solely a medical issue. Instead, the community is actively involved in caring, with support from health and social care services when needed.

> *"Death is not the opposite of life, but a part of it".*
>
> HARUKI MURAKAMI

We will all experience dying, death and grief. Yet on the island of Ireland today, we often fail to recognise or acknowledge these realities. While death and dying are natural and universal processes, many feel that families and communities have been pushed to the margins in favour of clinical intervention and healthcare systems. This imbalance encourages society to view death as a medical event, neglecting the suffering that occurs between diagnosis and death, as well as the grief that follows.

The recent Lancet Commission on the Value of Death highlights this shift, calling for a renewed focus on family and community involvement and emphasising that death and dying are an essential part of life. Dame Cicely Saunders' concept of 'total pain' reminds us that suffering extends beyond the physical to include psychological, social, spiritual, and practical struggles [3]. Communities can address these broader aspects of suffering in transformative ways by spending time with the dying, sharing laughter and tears, offering practical support, and simply showing compassion and care. Communities are uniquely placed to support each other through the entire journey of serious illness, dying, death and grief. In doing so, communities can help individuals live as fully as possible, right until the end.

The 95 percent rule [4], as identified by Prof Allan Kellehear (Northumbria University), states that a person living at home with a serious illness may only come into contact with healthcare professionals up to 5 percent of any day. As a community, what can we do to fill that other 95 percent with care and connection?

This critical question has inspired the development of 'compassionate communities'.

Caregiving, dying, death and grieving as everyone's business

The compassionate communities movement recognises that caregiving, dying, death and grieving are everyone's business. The approach advocates for a rebalancing of roles, where healthcare professionals support families and communities, rather than taking the leading role [5]. It is about respecting that individuals and communities know best what they need. The compassionate communities approach highlights that death is inherently relational and proposes a social model of care in which communities mobilise social networks, or "circles of care", to support individuals approaching the end of life [5]. This could, for example, be a group of neighbours who organise to support people in their area living with serious illness. Crucially, these circles of care are composed of both informal and formal support, ensuring continuity and high-quality care. We recognise that healthcare organisations do not bear sole responsibility for end-of-life care, and we should not desire them to.

It takes a village to raise a child- this is an African proverb we often use on the island of Ireland. It also takes a village to care for the dying and the grieving.

A New Public Health Approach

Compassionate communities are a new way of thinking about dying, death and grief, informed by the new public health approach; the idea that we all share a responsibility to care for each other physically, emotionally, socially and spiritually [6]. In this approach, communities work together to build their own capacity and skill in order to support people with serious illness at home, leaning on values like solidarity and personal agency. This support also extends to caregivers—family and friends—who often carry the greatest load in providing care [7].

By coming together, compassionate communities tap into collective compassion—a powerful, often-overlooked resource within communities that brings people closer, creating a network of integrated care and support for those who need it most [8].

Empowering Communities

At the heart of compassionate communities is the idea of empowering everyone to take action when it comes to serious illness, dying, death and grief [6]. This approach not only normalises these experiences but also shifts expectations around how death is managed and understood.

In a compassionate community, those with lived experience of caregiving, dying, death and grieving, are seen as valuable assets who understand what is needed to transform care for others. Their insights and experiences are essential in shaping the support systems that benefit everyone. Communities are encouraged to take the lead in providing care for their members at the end-of-life, with health and social care staff offering support and professional expertise where needed [9]. Working together by harnessing and connecting the skills and resources that exist in every community already (community 'assets'), compassionate communities can create an environment where individuals feel supported, understood, and empowered to support each other during life's most challenging moments.

Through harnessing community assets, compassionate communities offer opportunities and experiences that improve death literacy for their members, which is a vital component of how communities are able to support each other through caregiving, dying, death and grief. Death literacy is the knowledge and skills that enable us to engage in an informed way around issues relating to caregiving, dying, death and grieving. For example, someone who is death literate will be able to use their knowledge and skills to support an individual who is recently bereaved, or to provide practical support to a dying person.

Evolving Definitions and Frameworks

The compassionate communities movement is continually evolving and does not lend itself to a single definition. A commonly agreed understanding is that compassionate communities are;

"Communities that invest in and promote individual behaviour, group strategies or societal structures or policies that prevent or reduce suffering resulting from experiences of serious (mental or physical) illness, death, dying and loss; actively promote health and well-being, community support and empowerment of community members affected by such experiences; and actively acknowledge these experiences as natural parts of daily life" [6, 10]

Compassionate communities encompass a variety of different initiatives[11], reflecting the diversity of different communities. Compassionate communities initiatives are therefore unique as the evolving needs of every community are different. Based on their needs, compassionate communities include time-limited initiatives as well as continuous activity.

While formal health services have initiated many initiatives (i.e. a top-down model), communities themselves have also developed examples of initiatives (i.e. the preferred bottom-up model). Regardless, it is crucial that compassionate communities are anchored in a community development approach. It is proposed that higher levels of community engagement are required for increased empowerment, which in turn enhances health and wellbeing[12].

Key elements within compassionate communities initiatives include[13]:

- the provision of space and opportunity for discussion on dying, death and grief;
- community engagement and social actions driven by conversation on grief, end-of-life, and death literacy;
- support for those who are dying while living at home, and their carers, from formal volunteer programmes (or alternatively referred to as 'activated citizens');
- improved capacity for care and support to be provided by mainly community members, for people at the end of life;
- the continuation of social relationships for those living with grief, post bereavement[13]

Compassionate communities and compassionate cities working together

A new approach called the "palliative care new essentials" has been proposed to improve care for people nearing the end of their lives and their families. This model highlights four key elements needed to ensure quality and continuity of integrated care in the community: i) specialist palliative care, ii) generalist palliative care, iii) compassionate communities, and iv) civic end-of-life care (which we can think of as compassionate cities)[14].

Compassionate communities focus on local neighbourhoods, like a suburb or village, to bring people together and support one another. In contrast, compassionate cities operate on a larger scale, aiming to engage local governments and institutions to make broader, systems-level change. This includes involving different parts of the community, such as schools, workplaces, and trade unions, to improve the social and physical environments we live in. The goal is to create a culture of kindness and support, leading to positive changes in how we care for each other. This transformation is guided by the Compassionate Cities Charter, and helps strengthen compassionate communities[15]. When fostering a compassionate communities approach, this systems level change is essential alongside developing community capacity.

Compassionate communities as a global movement

Compassionate communities are an expanding movement, currently present within at least 19 countries around the world[16, 17]. In Europe, compassionate communities can be found in Austria, Spain, Sweden, Germany, Poland, Portugal, the UK, and in Ireland[16]. In the UK, Compassionate Communities UK serves as a network organisation, providing a community of practice for individuals and communities developing compassionate communities initiatives. The scope of these initiatives varies, with many connected to the hospice network.

Specific examples of compassionate community approaches in England include; school engagement with hospice[18], health professional mentors who towards the end of someone's life can map what support is available and slot into areas of need to provide extra support[19], and training for volunteers from the community in how to support and care for the frail and vulnerable[20]. So why are compassionate communities important to the island of Ireland?

THE RELEVANCE OF COMPASSIONATE COMMUNITIES TO THE ISLAND OF IRELAND

Fostering a compassionate communities approach across the island of Ireland could be pivotal in addressing the key challenges we face related to caregiving, dying, death and grieving.

Our changing demographic profile

People on the island of Ireland are experiencing caregiving, dying, death, and grief, now more than ever. We are witnessing a rapid ageing of our population both North and South, with the number of people aged 65 and over projected to increase by more than half over the next 30 years [21, 22]. Associated with this, a growing proportion of our population will be living for longer with serious illness and multi-morbidity [1, 2]. Over time, these demographic changes contribute to a steadily rising death rate [23]. As caregiving, dying, death and grieving become even more commonplace within our society, we need to build more connected, resilient communities that are better equipped to face these challenges together. By encouraging collective compassion and connectedness, compassionate communities can help ensure that no one faces these profound challenges alone.

Alongside our evolving demographic profile, is a shift in place of care. Over two-thirds of people on the island of Ireland would like to be cared for and die at home [24, 25]. While this desire is not currently a reality for most [25], projections suggests home deaths will rise significantly between now and 2040 [1, 2]. Dying at home can represent an aspect of a 'good death', however not every home death is a well-supported experience. Achieving a 'good death' at home requires sufficient support for carers, effective coordination with healthcare professionals, and the active involvement of the wider community [26]. A compassionate communities approach can help to ensure that families have the support and confidence needed to make a good home death a more achievable option.

Inequality at end-of-life

We have many diverse communities across our island, and unfortunately, we know that not everyone has equal access to palliative and end-of-life care. One key source of inequity is geographic location [27], where one third of our population are living in rural or remote areas. In these areas, the burden of serious illness and caregiving is particularly pronounced due to an older demographic and higher levels of unmet healthcare need [28, 29]. For children requiring end-of-life care living in rural or remote areas, there is only one children's hospice in the Republic of Ireland [30] and only one in Northern Ireland [31], and so their access to this service is limited. Existing health inequalities are exacerbated at the end of life. Individuals in rural areas are more likely to be engaged in caregiving than their urban counterparts [32], yet limited access to respite and the necessity of traveling over 90 minutes to reach hospitals can place immense strain on these individuals [32, 33].

A compassionate communities approach helps address inequalities at end-of-life by mobilising local resources and support networks that are closely attuned to unmet needs. Often, this involves identifying and addressing place-based unmet need. The result is empowering entire communities to provide support to both the individual with serious illness and the family, while caring or bereaved.

Social isolation & loneliness

Social isolation and loneliness pose significant challenges for people living with serious illness across the island of Ireland, compounded by the growing number of people living alone [23, 34]. Research with palliative and end-of-life care professionals in Northern Ireland highlights that individuals with serious illness face a particularly high risk of loneliness [35]. This group is uniquely vulnerable, as they

experience multiple risk factors for loneliness, including advanced age, declining physical abilities, and often financial insecurity.

Many in our communities have limited social contact, with some people with serious illness interacting only with the healthcare professionals who provide their care. One healthcare professional spoke about a conversation with a patient in the community, where the person had reflected: "*You're the first person who's sat on that sofa in 12 months*" [35]. This isolation is often shared by informal caregivers, who find themselves without the time or energy to maintain social connections. The emotional toll of this isolation underscores the urgent need for a compassionate communities approach to foster social connection, as advocated for already in a Marie Curie Northern Ireland report on loneliness [35]. A compassionate communities approach nurtures relationships through neighbourhood and community networks, providing a sense of security and belonging. For example, the Compassionate Communities Connectors programme in Australia which trained community volunteers, evidenced that the initiative was able to address gaps that formal service could not and particularly for those who lived alone, or were socially or geographically isolated [36, 37].

> *"When you lose someone you love, your life becomes strange, the ground beneath you becomes fragile... However, you are not alone."* JOHN O'DONOHUE

Unmet emotional and spiritual needs

Loneliness is only one of many emotional challenges that those living with a serious illness and their caregivers face. Serious illness can increase risk of psychological distress, anxiety, and depression [38]. Caregivers, who often provide more than 43 hours of unpaid care each week, are also at heightened risk of poor mental health outcomes [39]. Indeed, findings from a longitudinal study in Northern Ireland report both caregivers and those grieving the death of loved ones are up to 50 per cent more likely to face mental health problems than those not in caregiving roles [40].

Public health models of mental health and bereavement support, such as the four-tiered bereavement model [41], recognise that most individuals can cope with serious illness and grief through support from their social networks, without the need for specialist mental health intervention. A compassionate communities approach is central to ensuring that those facing serious illness, caregiving, or grief have access to this crucial social support. Indeed, some argue that we should reconfigure stepped care models to recognise that community support is the central component within the system. By mobilising informal care systems within the community and establishing a firm foundation, compassionate communities reduce the need for specialist services, helping individuals manage grief and mental health challenges in familiar, supportive environments. By embedding care within the community, compassionate communities create environments that buffer against the mental health impacts of caregiving and bereavement.

Need for cultural change around death and dying

Across the island of Ireland, death and dying are not routinely discussed within our communities. Various barriers exist to engaging in 'death talk', including a perceived lack of social acceptance or a fear of upsetting others [42]. One consequence of this is that only a minority of people have engaged in advance care planning [43]. Advance care planning is an ongoing process that supports adults of any age in sharing their values, goals and preferences regarding future medical care during serious and chronic illness [44] and is evidenced to positively impact the quality of palliative and end-of-life care [45]. In acknowledging advance care planning as a continuous process across the life course, we need to upstream conversations about death and dying.

Compassionate communities encourage open dialogue about dying, death and grief. They do this by creating a more supportive and understanding environment, where individuals feel more comfortable discussing and planning for end-of-life. This could be key to supporting wider engagement in advance care planning across our island, towards helping to deliver end-of-life care in line with individual goals and values.

Increased demand for palliative and end-of-life care

Although the need for a compassionate communities approach is broader than addressing the increasing demands on specialist and generalist palliative care services, by empowering communities to take ownership of dying, death and grief, this is likely to reduce reliance on overburdened health services.

Due to our changing demographic profile, it was estimated that between 2015 and 2046 in the Republic of Ireland, there will be an increase of 84 per cent in the number of people who will have a palliative care need (based on their disease) [1]. This means that Ireland will need almost double the provision of palliative care in only 30 years' time [1]. This is a considerable problem – how can access to, and quality of, palliative and end-of-life care services be improved, and quickly?

Investment in a compassionate communities approach would reform the model of care, so there is a less significant need to scale up current service provision. With an upstream focus on the population, it could ensure longevity and sustained change in how serious illness, dying, death and grieving are supported across the island of Ireland [6]. There is evidence of cost-savings to the health service from compassionate communities initiatives [14], where initiatives have demonstrated a reduction in unplanned admissions to hospital and fewer unscheduled visits to primary care and other allied health services [11, 46, 20]. For example, a compassionate communities initiative in Frome (UK) evidenced a 14% decrease in unplanned hospital admissions during the four-year study period [47]. In Australia the savings from delivery of the Compassionate Communities Connectors programme were reported at $518,701 AUD over 6 months, where they assumed enrolment of 100 patients [48]. Compassionate communities may also be a cost-effective choice for the patient and their families within the health system through less of a reliance on privatisation of care [49].

COMPASSIONATE COMMUNITIES AND NATIONAL POLICY

A strategic challenge for our shared island

Across the island of Ireland, we share in the challenges surrounding caregiving, dying, death and grieving. There is existing North/South policy alignment in the development of compassionate communities, as detailed below.

The establishment of compassionate communities and cities presents a strategic opportunity for North/South cooperation, which resonates closely with the broader aspirations of the Shared Island Initiative, working both within and across communities to build a more inclusive society. This approach seeks to bring those experiencing challenges around the end-of-life back from the margins. Numerous areas of North/South health cooperation have already demonstrated significant value, such as the North-West Cancer Centre in Altnagelvin, Derry-Londonderry. The *Inaugural Compassionate Communities in Palliative and End of Life Care Conference* which serves as the foundation of this position paper, was funded via the Shared Island Civic Society Fund, demonstrating the strong cross border dimension. Additionally, the Shared Dialogue Series on 'Working together for a healthier island' has underscored the potential for deeper collaboration in public health.

To build a truly healthy island, addressing suffering at the end-of-life must become an integral component of our public health approach. Investment in the development of compassionate communities is one key mechanism to deliver a better quality of life and death for all residents of our island.

Northern Ireland

The development of compassionate communities has been increasingly – if not explicitly- aligned with palliative and end-of-life care policy in Northern Ireland, making this an opportune time for committed focus. The evolving Programme for Government (2024-2027) recognises the need to transform the health and social care system through service reform and reconfiguration. Investment in compassionate communities would help increase capacity within health and social care and would address calls to deliver in innovative ways for communities across Northern Ireland.

The Regional Palliative Care in Partnership Programme, established in 2016, supports the delivery of quality palliative and end-of-life care across settings in Northern Ireland. One of four priorities of this programme (2023-2026) is 'Public Health Approach to Palliative Care'. However this programme is working to deliver on the *Living Matters, Dying Matters strategy* which, although emphasises the need for development of palliative and end of life care within the wider public health agenda, does not provide a specific mandate for developing a compassionate communities approach. The Public Health Agency has however provided funding for Compassionate Communities NI, a network of cross-sector organisations and individuals who develop a response to the challenges regarding end of life in all communities.

Investment in compassionate communities contributes to the ambitions of the new Northern Ireland Advance Care Planning Policy, by providing a context for more 'upstream' conversations around end-of-life and by providing a more comprehensive 'circle of care' through which end-of-life wishes can be realised.

The Department of Health Strategic Planning and Performance Group Health Service Executive in Northern Ireland is currently implementing a framework for an integrated care system. This framework aims to establish collaborative working across health and social care services and others such as local councils, service uses, carers and the community and voluntary sector to improve health and wellbeing and reduce recognised health inequalities. The complimentary vision of this framework to that of compassionate communities, suggests that establishing compassionate communities could provide the method for this framework to move forward.

Lastly, compassionate communities resonates closely

with broader health policy direction, such as Health and Wellbeing 2026: Delivering Together. This strategic plan recognises the importance of building capacity in communities and in prevention, including discussion of harnessing the existing assets within communities.

Republic of Ireland

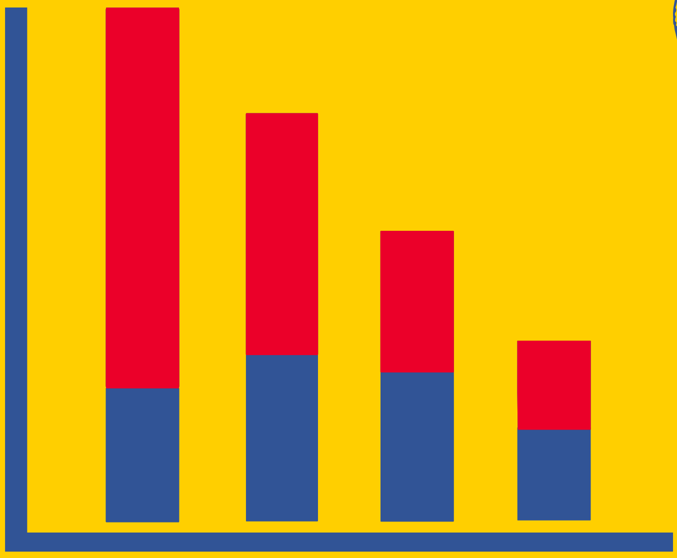
As with Northern Ireland, compassionate communities have been consistently aligned to palliative and end-of-life care policy across recent years. The 2020 Programme for Government emphasises the need to deliver more care in the community, with a particular emphasis on supporting older people to live in their own home with dignity and independence, for as long as possible. Investment in compassionate communities would help to deliver the continuity of care and place-based support needed to enable this policy objective.

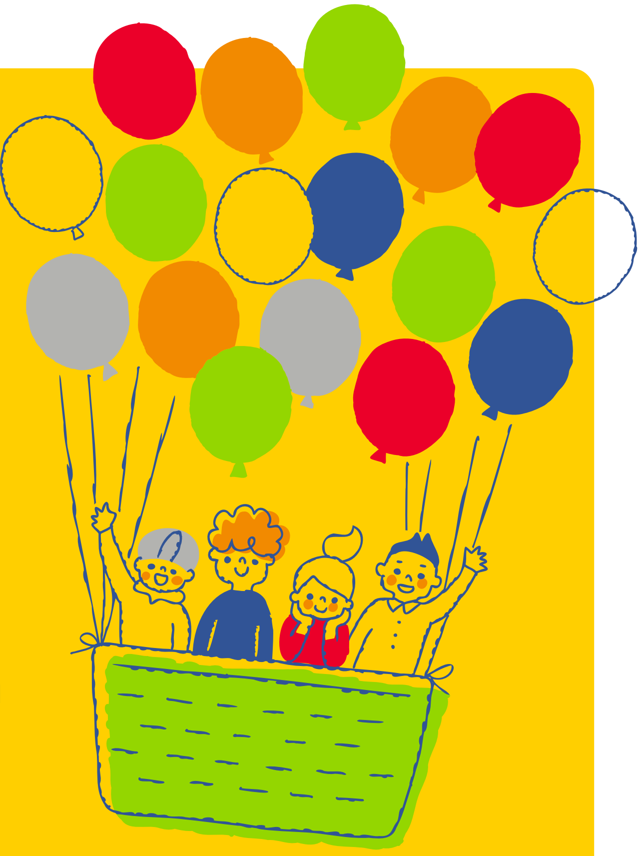
The new National Adult Palliative Care Policy was published in September 2024, explicitly recognises the need to integrate a public health dimension into palliative care. The policy includes a recommendation to support the development of compassionate communities. The activities associated with the recommendation include;

- Engage across Government Departments and agencies with the aim of empowering local government to mobilise available resources to address local needs for palliative and end-of-life care.
- Identify, evaluate, and implement exemplar models of community action in palliative, end-of-life care, and bereavement through competitive applications to the Sláintecare Healthy Communities Programme.
- Implement community development programmes in Regional Health Areas so that local citizens and specialist palliative care providers develop initiatives that build community action in palliative, end of life care and bereavement

The updated policy was preceded by various frameworks, such as the Adult Palliative Care Services, Model of Care for Ireland by the National Clinical Programme for Palliative Care, which emphasised the importance of a public health approach where the community are viewed as an equal partner in the task of providing quality healthcare. Compassionate communities were explicitly referenced as an example of the public health approach in action within this policy, in the form of the Milford Care Centre in Limerick [9].

Launched in 2021, the Sláintecare Strategy, aims to recentre Ireland's health care system to provide the majority of care within the community, in turn reducing health inequalities. The strategy also extends the work of the Healthy Ireland Framework 2019-2025, initiated in 2013. The Healthy Ireland Framework aims to work collaboratively across government departments and civic partners to empower individuals and communities to manage their own health and wellbeing. This strategy echoes the compassionate communities movement which also aims to make accessible community care a reality.





KEY FINDINGS FROM THE CONFERENCE

CURRENT PROGRESS IN DEVELOPING COMPASSIONATE COMMUNITIES ACROSS THE ISLAND OF IRELAND

We have established that there is a need to improve end-of-life and palliative care in the community, and that this is a priority in both Northern Ireland and the Republic of Ireland. Compassionate communities have been referenced as a vital part of developing our public health approach to palliative and end-of-life care, both in national policy and within consultation exercises[50, 51, 52]. The conference plenary sessions and discussion further evidence the necessity of investment in compassionate communities and cities, as a strategic driver for delivering this broader public health agenda.

The following section provides a synthesis of the key findings from the conference and reflects progress to date in fostering a compassionate communities approach across the island of Ireland, including both challenges and opportunities.

FINDING Compassionate communities initiatives need to be recognised as creating the environment for meaningful education, social awareness raising and open dialogue.

The importance of compassionate communities for creating the conditions for meaningful public education, social awareness raising and open dialogue around death was a recurring theme throughout the plenary sessions and roundtable discussions at the conference. Globally, these are central goals of many compassionate communities initiatives, serving as a crucial foundation for mobilising community action [53]. Compassionate communities and compassionate city initiatives create supportive environments for discussing dying, death and grief. By fostering partnerships and engaging communities, this approach ensures that people are not only informed but empowered to act.

Building a compassionate infrastructure

Sharon Williams is the Project Manager at Compassionate Communities NI, which was established in 2015 and has two hubs; in the Northern and North West localities. Compassionate Communities NI is a network of cross-sector organisations and individuals who develop a response to the challenges regarding end of life in all communities. Sharon spoke about how without openness and recognition of serious illness and death in the community, we risk leaving people alone, isolated – and this social isolation is a significant problem. Through compassionate communities initiatives, conversations about death can start to happen, so preventing what she described as a *social death*.

"*Dying over the last 50 years has happened predominantly in acute settings, and in nursing homes, and therefore we have lost the meaning in death. As a result, many of us feel disempowered to offer emotional and practical support. Sadly, this leaves those dealing with failing health and advanced illness, feeling socially isolated and lonely. And this social death is also experienced by our unpaid carers, and those living with bereavement*" (Sharon Williams, Compassionate Communities NI)

Sharon described the focus of Compassionate Communities NI in creating a *compassionate infrastructure* to increase death literacy. We know from previous research that there is opportunity to increase death literacy in communities across our island. We have untapped compassion within our communities- people want to know how to do better when someone is dying or grieving.

Sharon spoke to the achievements of Compassionate Communities NI in recent years, including the advantage of cross-sector working to co-develop events and educational resources between community and clinical staff. One initiative is the Compassion in Action Programme, which through workshops raises social awareness of how people can help each other and the impact of small acts of kindness. Partnership working has been at the core of all initiatives, some of which have included creating spaces for open dialogue about death within the community. One example is Death Positive Libraries, where an expanding list of libraries across Northern Ireland, and most recently in Cavan, have curated selections of books, articles and resources on a range of topics related to death and dying and, hosted death positive book clubs. Some libraries have also hosted workshop events such as 'Understanding Grief', have hosted a Before I Die wall, and have offered opportunities for people to connect with local support groups and services. This provision of space was also identified in the roundtable discussions as valuable for supporting development of compassionate community initiatives.

If we can work culturally, we can achieve so much

Sharon also emphasised the power of the arts for engaging the public in what can be a highly emotive topic. This was also a key message from Dominic Campbell, who has led the Irish Hospice Foundation's Arts and Cultural Engagement Programme since its inception in 2020. Dominic emphasised that in order to grow compassionate communities, we need to consider investing in and nurturing compassionate culture. Dominic described how working within the current culture of the community was crucial. Culture can include "language, ideas, beliefs, customs, codes, institutions, tools, techniques, works of art, rituals, and ceremonies, among other elements". Dominic referred to Prof Kellehear's reference to there coming a point in all of our lives when everything changes. We need to create a way through that, and we need to do that at scale. The global movement called 'arts in health' is trying to put together those tools for people.

"*In times when the narrative of life is broken, when you are bereft, people reach for arts and culture. For the manifestation of arts and culture. For all sorts of creative tools to help you navigate a journey of the spirit and of your community, and a time that is uncertain*" (Dominic Campbell, Irish Hospice Foundation Arts and Cultural Engagement Programme)

The Arts and Health Engagement Programme is informed by the IHF People's Charter on Death Dying and Bereavement, which aligns to a public health approach to palliative and end of life care. Dominic described how the programme's delivery mechanism starts with creativity and experimentation - getting people curious- and then moves into communication and education. Among developments has been investment in place-based community development (the Compassionate Culture Network), with a call for a healthcare professional and artist to develop a bespoke programme for their local community around exploring death and grief. This approach includes looking at the assets that are available in every single community, with the intention in Dominic's words to 'animate the culture' - make it normal to have conversations about dying, death and grief .

One of nine networks established to date has been in Buncrana, Donegal, led by visual artists Rebecca Strain and Martha McCullogh. Rebecca discussed how they worked with a small community group to deliver creative sessions including paper making, camera-less photography of special objects, and writing workshops - all exploring death and grief but in a gentle way. They started a Make 'n Mend Facebook group, for anyone not able to attend sessions but who would like to find creative ways to navigate grief. In these groups there was never any pressure to do anything, community members could just sit and chat. These arts-based initiatives didn't have agendas, and what developed was genuine community, and acknowledgment of grief in that community.

> *"I want to use art to help people to deal with things that they maybe can't talk about, or don't have the words for. And use it as a way of transforming"*
>
> REBECCA STRAIN, VISUAL ARTIST
> IN BUNCRANA, DONEGAL

Through the roundtable discussions, art was raised as being something of value when developing compassionate communities. Dominic also described the importance of place-based programmes- acknowledging that services are universal but not necessarily local. He emphasised the importance of accompaniment- having someone with you to navigate those moments when your life changes.

Opportunities for development

It was evident throughout the conference that a challenge is that there is a need to enhance understanding and awareness of caregiving, dying, death and grief. Encouraging people across our island to engage in conversations and learning experiences about death is essential and can improve our island's death literacy. Compassionate communities can create the supportive environment needed to not only inform but also empower people to take action.

The importance of raising social awareness about how compassion can be harnessed within communities was highlighted, as was the need to mobilise the compassionate communities movement across the island. This involves, as raised during the roundtable discussions, dispelling the notion that death and dying are matters solely for healthcare professionals. The need to work culturally was emphasised and recognising what that means for different communities across Ireland.

From the conference roundtable discussions, there were several good examples suggested which would assist in improving understanding and conversation about death. These included facilitating 'death conversations' in community settings, education on death and dying across the life course (including to children in schools) and initiatives broadly focused on improving death literacy.

The Caru Project

The Caru project, led by the Irish Hospice Foundation, the All Ireland Institute of Hospice and Palliative Care, and the HSE, is a continuous learning programme that is offered to every residential home in the Republic of Ireland. The aim of Caru is to support and improve the delivery of compassionate, person-centred, palliative, end of life and bereavement care to residents and family members in nursing homes.

The Caru Project supports the whole community of a residential home including the residents, staff, families, friends and kinship groups.

Linked to the 5 year programme, the Irish Hospice Foundation are supporting a project which aims to support conversations on dying, death and grief in residential settings using creative arts.

Six artists have been paired to a residential home local to them where they deliver innovative approaches to explore how art can open conversations about death and grief. Through dance, song, film, drama, poetry or storytelling, the challenges and griefs connected with residential care are addressed.

> *"It just opened the floodgates. I am here nearly five years, and I have noticed a big difference through the arts...Talking through arts is a great thing to me I think, because sometimes when your hands are doing, your minds not thinking, so you just go on...."*
>
> ACTIVITY COORDINATOR

FINDING On the island of Ireland, we must recognise, support and sustain initiatives that are driven by the community.

The conference highlighted that across the island of Ireland, numerous grassroots initiatives have been initiated and led by communities themselves. A key takeaway was the importance of recognising, supporting, and sustaining these compassionate communities efforts.

Internationally, compassionate community initiatives have taken many forms, with most following service-led, top-down models[11]. However, research suggests that community-driven, bottom-up approaches are often more effective in fostering long-term sustainability and scalability. These models empower communities to take ownership of care, initiating and delivering tailored responses to the unique challenges they face [12].

Sharon Williams highlighted the value of recognising existing community assets, particularly people with firsthand experience of caregiving, dying, death and grief. The community-driven initiatives described below have all been instigated by compassionate people living within our communities who recognised an unmet need and acted. They share a common thread- the projects recognise the power of lived experience within a network of care and the unique ability of the community to provide continuity of support. Prof Kellehear (Northumbria University) asserted in his address that true continuity of care is impossible without the active involvement of the community.

The power of lived experience

Eileen Pugh, whose husband Derek died four years ago, started M50 Soulfriends when she recognised the lack of space for people to openly discuss grief. Eileen shared how bringing together people who like her, had been widowed, created a profound connection based on shared experience. Initially organising small workshops, Eileen found that people were willing to travel long distances just to have a place to talk about grief. People wanted to be able to talk to others who had also lost their significant other, no one else understood what they were going through, and the events that Eileen organised where death and grief were simply talked about had immense value as a starting point.

> *“The profound transformation of people over even two days, over even three hours, is incredible. If they are with other people who get it”*
> EILEEN PUGH, FOUNDER OF M50 SOULFRIENDS

The M50 Soulfriends WhatsApp group was formed in 2022, with 12 original members, who came up with the idea over a dinner organised for widowed people. The WhatsApp group has now grown to 146 members. Eileen explains that anyone within the group can organise an event or activity and the community therefore manages itself. One of the members, Robert, who was recently widowed, talked of the significant gaps in care for people who are bereaved. Robert shared how vital it was to be part of a group who had gone through the same devastating experience;

“Everyone on it is like me. They have all lost their partners and are broken. They see the world in a totally different way. They have love and kindness to give. I breathe for the very first time in a very long time” Robert, describing his first experience of M50 Soulfriends

Like Eileen, Robert emphasises the lack of preparedness within communities to support widowed people. He describes how friends and family want to help, yet often don’t know how. Robert highlighted a resource which has been co-developed by M50 Soulfriends, with input from another bereavement support group in the UK, to provide guidance to those wanting to support someone who has recently been widowed. In his presentation, Robert urged the audience to think creatively and explore new approaches to lessen the immense suffering experienced around end-of-life.

The community providing continuity of care

Another grass-roots project discussed was a WhatsApp group for parents and carers of children with a life-limiting conditions. Samantha Villena (known as Sam) founded the group and is mum to Alex (17 years old) and Isabell (13 years old), who has a rare neurological condition (Aicardi Syndrome). Sam founded ‘Extra Special Kids’ support group in 2012, a year after her daughter was born. During that year, Sam had encountered mums in a similar situation to herself and identified the need for an online community so they could provide support to each other. Starting with just 15-20 members, the group has grown to 150 members from across the island, offering a vital emotional support to parents and carers.

> *“A lot of it is pure emotional support, because we all get each other. The kids have such a variety of conditions, and there is always somebody there who is going to give you their experience and just say we’re here for you. That’s it, we’re just here to listen to you”* SAM VILLENA, FOUNDER OF EXTRA SPECIAL KIDS CLUB

Sam highlighted that whilst healthcare professionals are so appreciated, they are not available to listen to you all the time, but the community can. Online communities can be particularly useful for carers, who can find it difficult to meet otherwise around caring responsibilities. Sam describes the group as a very positive and caring place, which largely manages itself. Sam talked about the maintenance of the community over time, and how bereaved mums often stay in the community and give advice. This can be so valuable for mums who are newly bereaved, as they know there are people in the group who are ready to step in and offer their support on that part of their journey. At the roundtable discussions support for carers was highlighted as a priority in the development of compassionate communities.

Sam discussed the power of personal experience, and the impact of just knowing that someone has gone through a similar experience to yourself. You can only get that from people who have walked in the same shoes as you.

Sharon Thompson is a member of the group, and a bereaved mum to her daughter Victoria, who needed palliative care in 2012. Sharon added that the group has come offline too, with some members meeting in person. The group had recognised that there was a need for activities for children with life-limiting conditions, who can sometimes find it difficult to attend camps and clubs. See below for more information about the 'Extra Special Kids' club for the children.

Sharon described how the evolution of the support group has involved many aspects of the compassionate communities initiatives discussed during the conference, and highlights the need to recognise, support and sustain initiatives that are driven by the community:

> *"This has all happened organically. And it is because people care, and want to support each other, and are showing compassion"* SHARON THOMPSON, MEMBER OF EXTRA SPECIAL KIDS CLUB

Developing links with healthcare professionals

A final example of a compassionate communities initiative was provided by Jaqueline Daly, co-founder of East Galway & Midlands Cancer Support. Jacqueline started the group after her husband was diagnosed with prostrate cancer and she recognised how little community support was available. Jacqueline described the journey of starting as a prostate cancer support group with no fixed premises, to establishing a support centre to provide a network of emotional, psychological and practical support to people living with cancer, their family and friends.

> *"Some of the things we have learned along the way are that it takes a village. It will never take one or two people to do what needs to be done"* JACQUELINE DALY, CO-FOUNDED OF EAST GALWAY & MIDLANDS CANCER SUPPORT

Jacqueline describes developing the project in line with unmet need in the community. The centre has 11 counsellors on board, offers numerous complementary therapies, and has built valued relationships with oncologists and consultants. This close relationship with the hospital is described as crucial and encompasses the majority of referrals to the centre. Jaqueline praised the work of Portiuncula's Nurse-led Oncology Unit, and described how the centre can support the unit by providing transport home for patients and their families after receiving bad news, and support the family to help put some sort of normality around the situation and make them aware of how they can be supported. The group recently bought a bus for trips to take members for radiotherapy sessions at Galway hospital. Jacqueline spoke about how this has inadvertently developed into a support group – a warm and positive space for people regularly making the journey. The centre also houses a gym and engages in supporting research projects where they can.

Jacqueline left the audience with a take home message - "*Those who say it can't be done are usually interrupted by others doing it*".

Opportunities for development

We know that compassionate communities initiatives are being driven by communities across the island of Ireland. Although it is clear that many of these initiatives developed organically, it is essential for us to foster the right environment that supports and encourages their growth. This includes empowering people within our communities to recognise the significant value that their lived experience can bring to the table. Many individuals may not fully realise that what they are doing aligns with the compassionate communities movement, nor understand the profound impact their actions have. It's vital that these contributions are recognised and celebrated, as they are integral to building compassionate communities. Health and social care professionals have a critical role in supporting these community-led efforts. By building bridges between formal healthcare systems and community initiatives (as has been demonstrated), they can help strengthen the capacity of these groups and ensure a continuity of compassionate care.

From the conference roundtable discussions, conference attendees suggested value in 'anything which would make people feel not on their own'. It was recognised that we need to expand our thinking to consider how compassionate communities can help achieve 24/7, continuity of care. The conference attendees emphasised the importance of peer support and of valuing lived experiences, and the need for support outside of healthcare settings (e.g. listening rooms for bereavement support). The importance of identifying existing compassionate communities initiatives to allow for signposting was also emphasised.

FINDING A considered community development approach is essential, to ensure local voices and needs are prioritised and sustainable change is achieved.

A clear message from the conference was that no compassionate community is the same. When asked for a 'best example' of a compassionate communities initiative, Prof Kellehear emphasised that "*every*

Extra Special Kids

In 2023, parents in Donegal decided to take the national online support group 'Extra Special Kids, Ireland' offline to create a club specifically for life-limited children.

The club is an informal group where parents communicate and arrange events with each other via a WhatsApp group.

Extra Special Kids provides a space that is too often unavailable for children with complex medical needs.

Through the club, children and their families are provided with a supportive environment where they can make memories to last a lifetime. The club engages in many activities including messy play, music therapy, coffee mornings, mothers meet-ups and come Christmas time, Santa videos.

> *"We created a community of parents of children with disabilities and complex needs so that we could provide a social and fun friendship experience for our gorgeous children who don't get to have the experiences that neurotypical children have. We also created this space so as carers and friends we have our "tribe" so we can support each other."* A MOTHER OF A CHILD WHO ATTENDS THE CLUB

community is different, and so every compassionate community is different". He illustrated the diversity in how existing compassionate cities across the globe have developed; the compassionate city of Ottawa (Canada) was led by businessmen, the compassionate city of Bern (Switzerland) led by palliative medicine physicians, the compassionate city of Frome (England) led by the local primary care services and compassionate Seville (Spain) led by the church. Regardless of how they develop, it is essential to ensure that the voices of the community are front and centre. The direction provided from the conference was clear: compassionate communities are built when a community's voices are actively listened to and respected.

Voice and focus of compassionate communities

No two communities are the same. What one community has in terms of assets - the people who live there, organisations, and services - will be different from another community. The same is true for what a community does not have. Therefore, the unmet needs of every community are unique.

Compassionate community initiatives can be developed by whoever hears the voice of the community, recognises the unmet need and has the motivation to make a change. Jaqueline Daly from East Galway & Midlands Cancer Support is an example of how successful compassionate communities are built using the voice of a community. When Jacqueline's husband was living with prostate cancer, she was disappointed by the lack of dignity he received in his care and decided to address the issue head on for other people and families in the same situation. Upon doing so, other members of the community with similar issues came to Jacqueline for help. The community met regularly to voice what the unmet needs of the community were. This in-depth understanding of unmet need within a particular community informed the development of East Galway & Midlands Cancer Support.

During the conference, attendees recognised that it is difficult to hear the voice of the community when individuals don't know how to engage with community members. Alison Bunce, who is the programme lead for Compassionate Inverclyde, a compassionate community initiative based in Scotland, made numerous suggestions on how a community's voice can be encouraged and amplified. Such suggestions included developing a steering group with community members, holding 'listening events' where community members are simply asked what a compassionate community would mean to them, as well as holding public events and using social media to recruit volunteers. The importance of taking the time to engage with the community to listen to their voice was mirrored through the conference roundtable discussions. Conference attendees noted the importance of extending invitations to community members and organisations to both understand unmet need and to co-develop initiatives to address unmet need. It was also noted that every effort must be made to engage with people with valuable lived experience of caregiving, dying, death and grief as they can provide insight into what is missing, lacking or could be done better.

The answer of how to develop a successful compassionate communities initiative lies within the community itself. Listening to the voice of the community provides a natural, grassroots starting point. If a compassionate communities initiative speaks to the heart of the community and gives people a belief in what they are doing, it will more than likely be sustained.

Developing a compassionate community requires time, patience, and trust. Alison Bunce shared that it took five years to fully realise the vision of 'Compassionate Inverclyde' and a full year just to launch. Building relationships, listening to various groups, and understanding their needs was essential.

"It didn't officially launch until 2017 and why? Because it was so important to hear the voice of the community. It was so important to build the relationships up in the community, to actually understand what does our people want, not want we think as professionals that they would like." (Alison Bunce, Compassionate Inverclyde).

Compassionate communities need active and systematic engagement

As discussed by Dr Guy Peryer (Director of Education & Research, St Christopher's Hospice), community engagement is essential to the success of compassionate communities. However, for engagement to be impactful, it needs to be both active and systematic. Firstly, engagement must be systematic as you need to identify organisations and individuals who can help build the compassionate communities initiative and plan how you are going to approach them. Secondly, the engagement must be active. Active engagement means using civic orchestration to build, bridge and link social relationships between the community, generalist services and specialist services.

Sharon Williams from Compassionate Communities NI, demonstrated how active and systematic engagement is behind the success of their compassionate communities initiatives. Compassionate Communities NI was formed by a cross-sector partnership between Compassionate Communities North West and Compassionate Communities Northern. The linking of the two organisations combined staff knowledge and skills to create a stronger collaborative effort to raise awareness across NI. Compassionate Communities NI has since identified and collaborated with various other organisations across NI to further enhance engagement. Sharon Williams discussed an example of an event that was held to engage women from farming families in succession planning, where Compassionate Communities NI collaborated with Northern Trust Rural Support and Ulster Farmers Union. The event was very successful, with people having to be turned away at the door. The building, bridging and linking of professional relationships has been essential for their work as the reach of the work of Compassionate Communities NI relies on community partners and champions.

> *"The project has been able to evolve and develop its scale, having a wider impact because of the partnerships and working with others."* (SHARON WILLIAMS, COMPASSIONATE COMMUNITIES NI)

Moving forward with collective action

Active and systematic engagement can be difficult in the current unsettled times. Dr Guy Peryer acknowledged that recent and ongoing world events, such as the COVID-19 pandemic, cost of living crisis and war in Ukraine, may mean that people are less able to mentally commit to engaging with compassionate communities initiatives. Additionally, those willing to engage often face barriers such as resource constraints, complexities in the care system, and inadequate support for diverse care needs. Overcoming these challenges requires collective action and collaboration. As Dr Peryer stated, *"If we're going to move forward, we need to move forward together."*

To move beyond the barriers, Dr Peryer recommended building systematic engagement. To build systematic engagement, communities need to identify the strongest existing relationships within them - "*start with what's strong, not with what's wrong*". Dr Guy Peryer also drew upon Marshall Ganz's 'Power of Story' theory [54]. To encourage active engagement, it is important for people within a community to understand why me, why us, and why now? Once individuals understand the importance of their role, it is essential to equip the inner networks available to people when dying, since the best support comes to people from those who know them the best. Equipping these individuals will ultimately strengthen the community network, as a network is only as strong as its individual links. Dr Guy Peryer also gave a general example of what the structure of an engaged compassionate community could look like, with a core steering group- approximately eight people- at the centre, and several spin-off small groups dedicated to addressing certain unmet needs within the community, such as a group for the homeless.

Opportunities for development

Communities across the island of Ireland possess a wealth of strengths that – once identified- can be leveraged when developing compassionate communities initiatives. A strength-based approach is essential to recognising existing assets, while addressing unmet needs. In the roundtable discussions, conference attendees recognised that we have various community groups across the island who could be supported – with the right capacity- to deliver compassionate communities initiatives.

Community engagement ranges across a continuum; from informing and consulting, through to co-production, collaboration and empowerment, with the latter aligned to building community capacity to identify and solve their own issues [12]. If compassionate communities initiatives are not instigated by community members themselves based on local need, organisations need to be aware of the level at which they are engaging with communities and ensure community voices are front and centre.

Working *with* as supposed to *in* communities requires appropriate time and resource, and there are opportunities for us across the island to ensure the voices of local community members are amplified. Ensuring meaningful and sustained community engagement is key to fostering compassionate communities that lead to real, lasting change across our island. The roundtable discussions frequently emphasised a need to create the opportunities for community engagement, through inviting communities to open forums to discuss local needs and potential solutions. There was also the suggestion to establish a publicly available database, detailing community assets and needs, to inform the development of compassionate communities initiatives in partnership.

FINDING Inspiration and practical guidance are necessary to mobilise existing communities on the island of Ireland to develop compassionate initiatives.

The conference was filled with enthusiasm and a strong commitment to making compassionate communities a reality on the island of Ireland. Expert speakers delivered positive and inspirational talks about the potential of these initiatives. However, from the questions raised and discussions throughout the event, it became clear that many attendees were seeking not only inspiration but also practical guidance on how to begin building their own compassionate communities initiatives. There was a clear desire for concrete steps to help turn this vision into actionable plans at the local level.

It begins with you

A key message from the conference was that the responsibility is on all of us to develop compassionate communities. Speakers throughout the event, highlighted the importance of not waiting for someone else to make the change and to make the change ourselves. It was clear that just getting started is the key. For example, starting to have conversations with organisations around the community, or as Eileen Pugh

Rosie's Trust

Rosie's Trust keeps people and their pets together.

Rosie's Trust is the only charity in Northern Ireland that is dedicated to support people who may be receiving cancer treatment, end of life care or are elderly with a disability look after their pets.

Approximately 212 Rosie Trust volunteers visit people's homes 365 days a year to provide free support to care for their pets through feeding, grooming, exercising, playing and taking them to visit the vet. Through these visits the volunteers build valued relationships with the pet owners.

Since 2015, Rosie's Trust has supported approximately 217 people keep the joy and love this companionship brings to their lives when they need it the most.

> *"Rosie's Trust comes out to me and walks Finn every day – not for money or profit, but for a genuine love for my dog. Finn benefits so much from this and me too; I have peace of mind that he is getting what he needs while I'm not able to do all I can for him."*
>
> COMMUNITY MEMBER SUPPORTED BY ROSIE'S TRUST

from M50 Soulfriends did, simply find a venue, advertise on social media, and invite people to meet to talk about grief.

"I then set about trying to gather people, I knew that if I was desperate there must be other people. So I did a workshop 'lets talk about death'...I ran a couple of retreats...I organised a few walks because there was nothing in Dublin..." (Eileen Pugh, M50 Soulfriends)

Prof Kellehear highlighted that people commonly forget that they too will die someday. Therefore, what we do today to build compassionate communities will not only benefit other people but also ourselves. Keeping our own immortality in mind should serve as motivation to build compassionate communities. Alison Bunce, founder of Compassionate Inverclyde, reiterated that ordinary people make a difference together, and everyone has something to offer someone else. Compassionate communities start from a desire, that turns into a vision, and then to action. Developing compassionate communities initiatives is up to all of us.

"Theres no time like today and the phone is at the end of your hand" (Professor Allan Kellehear)

Compassionate communities can begin with simple actions, and impactful initiatives may not directly or conventionally focus on healthcare. During roundtable discussions, attendees suggested practical ideas for compassionate communities initiatives for our island. These included caring neighbourhood watch programs, befriending services, connecting existing men's and women's sheds (and other existing organisations) and creating support guides for grief and illness. These realistic steps provide a clear starting point for communities looking to foster compassion and support.

A roadmap is needed

It was clear that the conference attendees were grateful for the real-life examples of compassionate communities projects that were provided during the conference. Each compassionate communities initiative was different and during the panel discussion, conference attendees questioned what the structure of a compassionate community should look like - whether it is better to have one large, coordinated effort or to have smaller efforts spread throughout the community. Prof Kellehear noted that we must be wary of a compassionate community growing too large and instead of focusing on getting bigger, the focus should be on breeding – encourage smaller communities to start around you rather than enveloping every initiative under one banner.

Whatever the roadmap to developing a particular compassionate community looks like, it's okay to go off track. When developing compassionate communities, not everything will go according to plan, and that's okay.

"A lot of this stuff we can't pre-plan, we've got to be open to unanticipated consequences...let's be open to all of the benefits that could happen." (Dr Guy Peryer, St Chrisopher's Hospice)

Opportunities for development

Conference attendees expressed a desire for a 'roadmap' or DIY toolkit to developing compassionate communities initiatives. Although it wouldn't be appropriate to be prescriptive, in terms of respecting that each community is different, it is reasonable for us to provide inspiration and practical guidance to those across the island who have an interest in developing their own initiatives. The roundtable discussions highlighted the need for examples of successful initiatives, and we are able to look both across the island of Ireland and further afield for these.

In particular, there is significant learning to be shared from those individuals and organisations identified throughout this position paper, and many others besides, who have developed and delivered compassionate communities initiatives. They too are valuable community assets and it is important that we retain their knowledge and experience, and facilitate mentorship and partnership working where we can. We also have the international community to draw upon.

FINDING Engagement from civic society across the island of Ireland is needed, to embed policies and support around caregiving, dying, death and grief within all our key institutions.

In order to foster compassionate communities across the island of Ireland, it is essential that we support grass roots initiatives and services working in close partnership with communities. However, a key message throughout the conference was the need to balance this with higher level support and systemic change across civic society. Civic society needs to be engaged and engaged beyond the context of health and social care. This is absolutely critical if compassionate support is to be available to people affected by serious illness, in all aspects of their lives.

A social ecological approach

Prof Kellehear (Northumbria University) emphasised the importance of a social ecological approach to the development of compassionate communities. This involves recognising how interactions between individuals, communities, and their broader social environments influence care and support for those facing serious illness, dying, death or grief. It recognises that people are embedded in multiple layers of social contexts—familial, community, cultural, institutional—and that compassionate care requires engagement across these interconnected layers.

The Compassionate Civic Charter

Dr Peryer (St Christopher's Hospice) echoed this, emphasising how equipping communities to be compassionate requires a community focus supported by a broader sociological approach, which can be usefully guided by the Compassionate City Charter. This is where whole cities or towns develop policies across their sectors. The Compassionate City Charter, co-developed by Prof Allan Kellehear, proposes that a city council will develop and support 13 social changes to the city's key institutions and activities. This for example includes; establishing policies within schools for care, dying, death and grief, having dedicated groups for end-of-life care support within places of worship, and promoting compassionate communities programmes in local neighbourhoods. This charter has also been amended to a Compassionate Civic Charter, recognising more explicitly the need to support work across both rural and urban communities (e.g. across council areas).

"In the matter of social, psychological and spiritual, every social institution in our society can provide palliative care and should. The workplace, the schools, the arts community, the neighbourhoods, the local government, the football club, the golf club. Each and every one of these institutions should provide palliative care because each and every one of them provides health care" (Professor Allan Kellehear, Northumbria University)

Ultimately, the development of partnership working at multiple levels was stressed as essential. During a panel discussion, Alison Bunce (Compassionate Inverclyde) discussed the development of relationships with local councils as having been key to the success of Compassionate Inverclyde. The benefit from these relationships will trickle both up and down, with compassionate communities and compassionate cities sustaining each other. The message was that you can of course still start grass roots, but it serves to court the leadership.

Palliative care as a civic responsibility

Prof Kellehear described how the city charter can be used as a tool to guide and regulate systematic cooperation in policy development. These policies need to be implemented, allowing public health funding and resources to be utilised to start, nurture, and grow compassionate communities. Hospices, palliative care services, and the community need to be empowered to contact civic institutions and ask what their palliative care policies are. This civic policy development is an important approach when engaging the community in palliative care.

"Every civic institution in our society should have palliative care policy - what palliative care are they providing? And only when that happens can we talk about continuity and quality of palliative care. Continuity and quality of palliative care is not just a matter of switching from doctors to social workers, or social workers to occupational therapists, it's about handing the patient back into their community, and find out how the community is continuing that palliative care when that adult or child goes back to school, back to the retirement home, back to shopping, back to the neighbourhood, back to the workplace, and back to worship. That's continuity of care, and it's where in the end palliative care becomes everybody's business." (Professor Allan Kellehear, Northumbria University)

In the U.K examples of already existing compassionate cities are Plymouth, Sheffield and Birmingham. Compassionate cities and compassionate communities, as long as partnership with health and social care providers is present, can and should be run by anybody. To date across the island of Ireland, Derry-Londonderry is the only city to develop a Compassionate Cities Charter

Opportunities for development

There is significant opportunity for local government, government departments, councils and civic institutions, both North and South, to help lead the way in prioritising a compassionate approach to caregiving, dying, death and grief. The Compassionate Civic Charter provides

Marie Curie Schools Bereavement Programme

Over the last 2-3 years, Marie Curie has developed the Schools Bereavement Programme to strengthen grief education and bereavement support in schools.

The programme has four phases.

1. Teacher training on loss and bereavement
2. Developing and delivering a loss and bereavement module
3. Analysing attitudes to grief education
4. Promoting the module and grief education to be embedded into the school curriculum

The programme has been piloted to 374 teaching staff across 162 schools in Northern Ireland.

Teachers' ability and confidence to support pupils with bereavement improved by 52%.

This training then kickstarted changes to be made to school policies:

"… we were able to use a lot of what I had learned at the course … So a new version of the policy is now in place." (Senior Teacher)

Not only did teachers and schools benefit, but also the pupils and their families, as the programme created a supportive environment for families to process their grief.

> *"I'm a teacher of over 30 years' experience. I went into the course thinking what can they really tell me that I haven't already experienced? But no, I left there with many more tools for my toolbox."*
>
> SENIOR TEACHER

a systematic approach to ensuring engagement from all sectors of society. After the conference, Public Health Palliative Care International published the Bern Declaration 2024, which similarly urges governments, city administrations and all civic organisations within communities and cities to commit to a number of key health promotion principles and actions for the end of life for ALL people. Engagement with such frameworks would ensure that all sectors of our society—from schools and workplaces to local governments—actively participate in supporting individuals experiencing caregiving, dying, death and grief.

During the conference roundtable discussions, conference attendees proposed several actionable steps which align to this key message. Suggestions included implementing the Compassionate Civic Charter through local councils, establishing recognition programs and awards for compassionate groups and individuals, and developing practical palliative care policies within our public institutions. Increased resourcing of existing initiatives was also mentioned, including a role for closer collaboration between Departments of Health, Education and Communities to support the expansion of programmes which have started in libraries and schools (see Compassionate School Communities report) and to look for other opportunities for partnership working.

FINDING Strategic leadership and investment is essential to foster compassionate communities across the island of Ireland.

At the conference there was acknowledgement that a compassionate communities approach needs to be a central component of future palliative and end-of-life care on the island of Ireland. The reference to developing a new public health approach to palliative and end-of-life care in the Northern Ireland Regional Palliative Care in Partnership Programme was highlighted within the conference, and just after the conference we saw explicit reference to compassionate communities within the new National Adult Palliative Care Policy in Ireland. Top-down support to resource these key policies, as mentioned by several of the speakers, is absolutely essential if we are to see compassionate communities integrated into care for those at end-of-life across our island.

Cross-border collaboration

Tánaiste Michael Martin, delivering the conference opening address, emphasised that North/South collaboration needs to be deepened where it makes eminent sense to do so, with healthcare being one such area. The Tánaiste emphasised the importance of opportunities such as the conference, for providing a clearer understanding of the ways in which North/South cooperation can be further harnessed. He expressed a desire to see more proposals for cross border co-operation from health practitioners. The Tánaiste made a point of emphasising the strength of the hospice movement across the island, as well as the significant value of our family/unpaid caregivers.

Indeed, many of the compassionate communities initiatives discussed at the conference, and highlighted in the exemplar projects throughout this report, have an element of cross-border co-operation. For example, Sharon Williams (Compassionate Communities NI) acknowledged the importance of cross-border collaboration in her presentation and emphasised that there is significant opportunity to develop compassionate infrastructure while thinking in cross-border terms. Sharon mentioned that Compassionate Communities NI are collaborating with Cavan County Council and the Irish Hospice Foundation, on a project called the Art of Life (see below). This cross-border collaborative project aims to normalise conversations around dying, death and grief using arts-based activities to help people reflect on what is important to them, so they can plan for later years with agency and independence.

The need for strategic leadership

The need for strategic leadership to foster a compassionate communities approach across the island of Ireland was referenced within the conference presentations and roundtable discussions. The conference profiled a number of organisations (e.g. Compassionate Communities NI, Irish Hospice Foundation) who are each delivering larger programmes of work around compassionate communities. We do not however have an organisation with the resource needed to support a compassionate communities network across the island. In the roundtable discussions, the need to either identify or establish an organisation to provide strategic leadership and vision for compassionate communities across the island of Ireland was endorsed. This organisation needs an appropriate level of Government investment, so that they are able to deliver on the sustained and long-term change needed. Aligned to this, conference attendees referenced the need to support compassionate communities champions across different sectors.

Financial support directed to the community

It was mentioned on numerous occasions throughout the conference how individuals and organisations managed to start and sustain compassionate communities initiatives with no financial backing. Had there been money available some of these initiatives would have availed of it, but they weren't going to let the lack of budget hold them back. However, it leaves us with

The Art of Life

The Art of Life is a cross-border project which aims to normalise conversations around death and dying using creative approaches.

This project is led by 'Creative Cavan' who have collaborated with the Irish Hospice Foundation, Compassionate Communities, Cavan Age Friendly, South West Age Partnership, Healthy Ireland at your library, Libraries NI and Cavan Library Service.

The project will be delivered during 2024 and 2025 and 'creatives', care professionals and the wider public will work together to maximise reach and build a lasting legacy.

The 'creatives' (artists) will be trained to lead the project and deliver a range of events across Cavan, Fermanagh and Tyrone.

Several death positive libraries and reading lists have been developed and an art piece reflecting the project has been commissioned that will be donated to a meaningful location.

> *"My heart and chest felt really warm after this - I felt as if the block of ice, that has been around my heart for 20 years, had melted. The opportunity to talk about death and dying was brilliant! I honestly feel this project should be made available to more people and groups. It is so beneficial."*
>
> PARTICIPANT IN AN 'ART OF LIFE' PROJECT

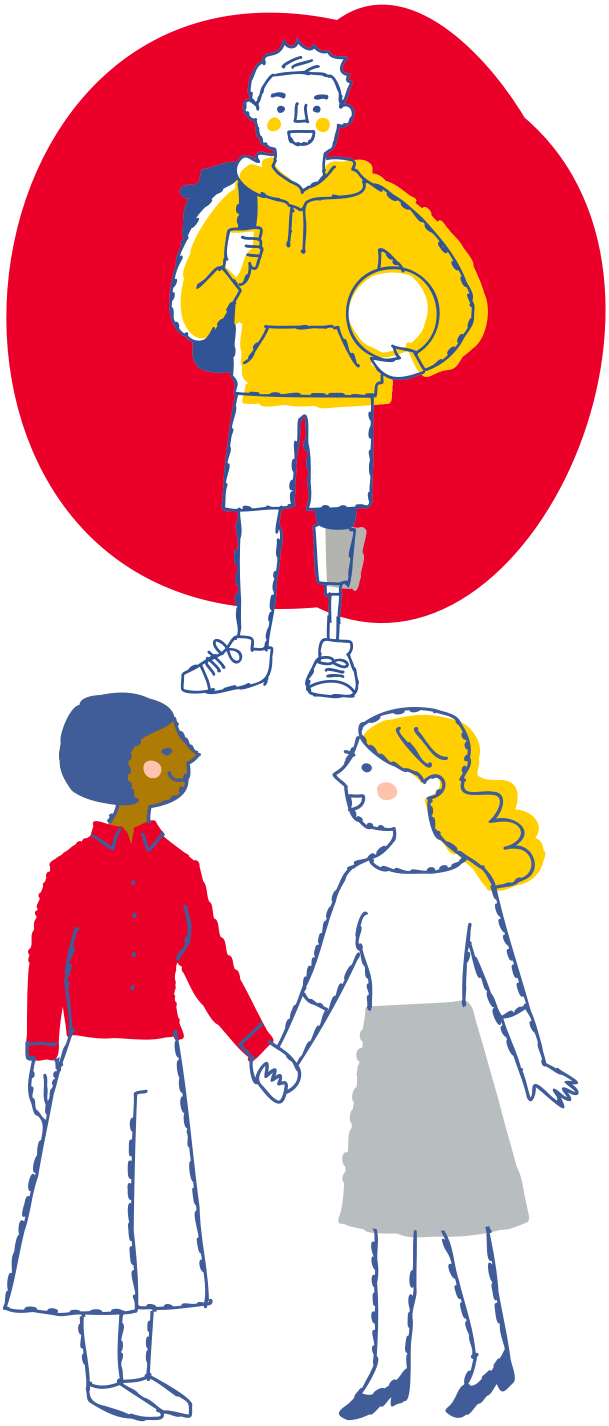
the question: why is there no money to support these initiatives? Compassionate communities are referenced within key national policies North and South, yet it is unclear how the movement can expand and be sustained for long enough to impact public health, without being valued through financial investment.

During a panel discussion, a community group leader from Lurgan echoed the speakers' sentiments that fostering compassionate communities is largely about stepping up. They described their group as having received little to no funding, yet they remain hopeful about growing and delivering initiatives similar to Compassionate Inverclyde, as outlined by Alison Bunce. While their passion and dedication will undoubtedly drive their success, one can't help but wonder how much more impactful or innovative their efforts could be with even modest financial support. Such backing could provide the resources needed to establish and sustain meaningful initiatives within their community.

Dominic Campbell (Irish Hospice Foundation) highlighted the value of financial support, noting that over the last three years, the Irish Hospice Foundation's Arts and Cultural Engagement Programme has been offering microgrants and mentorship to help people address the specific needs of their communities around the realities of dying, death and grieving. At least 62 microgrants have been awarded, which has enabled the creation of diverse initiatives, such as a graphic novel on perinatal grief and a project by bikers exploring how to memorialise their community members. These projects have led to a groundswell of conversation around dying, death and grief- both within communities but also online through the digital legacy of these projects. This is a clear example of how even modest financial support can unlock creative potential, enabling projects that might otherwise never have materialised. In the roundtable discussions, general financial priorities focused on increased funding, including seed-funding to enable smaller projects which could be appropriately evaluated and expanded, as well as incentives to enhance the well-being of volunteer carers, such as carers' credit.

Opportunities for development

Delivering on a compassionate communities approach is essential to ensuring that caregiving, dying, death and grieving are supported with dignity and care across the island of Ireland. As the Tánaiste highlighted in his address, there is an ongoing need for political and financial investment in healthcare, and this is particularly the case when it comes to fostering the compassionate approach to end-of-life care that the people of this island deserve. Throughout the conference, successful compassionate community initiatives were showcased, often driven by small groups of dedicated individuals. However, we cannot and should not rely on compassion alone to sustain these efforts.



Many existing compassionate communities initiatives across the island face significant challenges with either a complete lack of or else short-term funding, which limits their sustainability and potential reach. If we are to develop a compassionate communities approach at scale across the island, we need investment to build the appropriate infrastructure and investment in our communities. We also need to recognise the substantial experience and knowledge held within individuals, groups and organisations who have developed and led compassionate communities initiatives, and the importance of ensuring we retain this. We are a small island, and there is considerable potential for cross-border collaboration, enabling the sharing of resources, expertise, and successful strategies.

CONCLUSION

Across the island of Ireland, there is a pressing need to transform our experiences of caregiving, dying, death and grieving. Communities are uniquely positioned to support people to live as well as possible, until the end-of-life. This position paper highlights how fostering compassionate communities can address the challenges we face as an island which are associated with serious illness, while also aligning with key policy developments. Fully realising the vision of a compassionate approach to serious illness requires dedicated top-down support – both to ensure the right environment to support meaningful community development and also to achieve the systems level change needed to embed compassion across all sectors of society.

Empowering communities to lead in supporting those affected by serious illness, with the support of our valued specialist and generalist palliative care services and wider civic society, is vital for ensuring quality, continuity, and equity in care. To balance these care elements, there is an urgent need to increase community capacity around caregiving, dying, death, and grieving, and to drive broader systemic change across civic institutions. A strengths-based approach, which builds on existing compassion within communities across the island, will amplify the voices of those with lived experience, fostering a deeper understanding of place-based needs. Alongside this, the development of compassionate civic charters is essential to both support community efforts and to ensure that individuals affected by serious illness encounter compassion in every aspect of their lives.

A social ecological approach, as emphasised by Prof. Kellehear, underscores the need to nurture compassion at every societal level, from families to institutions, ensuring caregiving, dying, death, and grieving are seen as collective responsibilities. Cross-border partnerships offer further potential, allowing resources and expertise to be shared for the benefit of communities across the island. By uniting community-driven action with robust support from wider civic society, the island of Ireland can cultivate a compassionate culture that transforms care for those facing serious illness, death, and end-of-life challenges.

Recommendations

These recommendations are informed by the key findings of this position paper and have been refined through workshops with key stakeholders. They are grounded in the principle that people with lived experience and communities themselves must be at the heart of delivering on each recommendation. It is essential that communities are engaged as active partners—not only as recipients but as co-creators who shape, implement, and sustain these initiatives. Their insights, needs, and strengths should guide every phase, ensuring that each action is relevant, empowering, and responsive to local contexts.

Caregiving, dying, death and grieving should not be the responsibility of health and social care. As such, it is our position that to deliver on the following recommendations, a clear mandate for fostering compassionate communities is needed from local government both North and South, with the recommendations translated into specific actions and delivered through relevant government departments.

Recommendations

1 Advocate for the adoption and implementation of this paper's recommendations by engaging with local government, government departments, councils and civic leaders

Achieving meaningful change in how we experience caregiving, dying, death and grief across the island of Ireland requires committed, top-down support. There is a need for collective action to lobby local government, government departments, councils and civic leaders, to ensure they understand the need for compassionate communities and agree to adopt and deliver on the recommendations in this report to ensure the people of this island receive integrated compassionate care in all aspects of their life and death. There is alignment between compassionate communities and key policies within health and social care. However, it is essential to recognise that developing a compassionate approach to caregiving, dying, death and grief should be a shared responsibility across all government departments, councils and civic institutions. As such, fostering a compassionate communities approach should be mandated for at a local government level.

2 Support/establish an organisation with secured funding for at least five years to provide strategic leadership and act as a knowledge broker for compassionate communities across the island of Ireland

There is need to support an existing organisation, or establish a new organisation, to provide strategic leadership to foster compassionate communities across the island of Ireland. This would include hosting a network, in order to support partnership working, knowledge exchange and awareness raising activities. This would necessitate longer-term investment and appropriate staffing, which would enable the organisation to take the lead on delivery of the subsequent recommendations, in partnership with other key organisations, and with the community at its centre. The organisation could be funded through cross-border investment, enhancing the vision of the Shared Island Initiative, where all communities across the island of Ireland work together towards a shared (and more compassionate) future.

3 Deliver public awareness campaigns around the concept and benefits of compassionate communities, linked to providing recognition and reward to existing initiatives

To help mobilise community action, there is need to increase social awareness across the island of Ireland about both the concept and benefits of compassionate communities initiatives. This should be linked to providing recognition and reward to existing initiatives. Such public awareness raising activity could be embedded within existing campaigns to raise awareness and understanding of palliative care; a recommendation within the new National Adult Palliative Care Policy (2024) in Ireland and delivered within the Regional Palliative Care in Partnership Programme in Northern Ireland.

4 Commission and complete an asset-mapping exercise to identify compassionate communities initiatives and community groups with potential to deliver initiatives across the island of Ireland. The results should be published in a publicly accessible online map and updated every six months

A comprehensive understanding of initiatives being delivered which align to a compassionate communities approach is required, alongside identifying existing community groups who could be supported - with additional capacity building activity - to deliver such initiatives. Asset-mapping needs to be preceded by public awareness raising activities (*see Recommendation 3*), in acknowledging that individuals and community groups may not easily identify with the compassionate communities movement.

5 Facilitate engagement workshops in communities across the island of Ireland, to identify local need and establish partnership working between communities and health and social care

Creating regular opportunities to amplify the voices of those who have lived experience of caregiving, death, dying and grieving is vital. Consideration of equality and diversity should be at the forefront when planning, to ensure the full diversity of voices from across our island can be heard Engagement workshops will foster relationships and ultimately build trust with the community, including both individuals and community groups existing there (linked to Recommendation 4). The engagement workshops are a key opportunity to promote access to seed funding and mentorship (Recommendation 6). The importance of establishing the community as an equal partner in care has long been highlighted in North/South policy. Only by engaging with communities will it be possible to create specific priorities and identify action which will have meaningful results for that specific community and in alignment with their unique culture.

Recommendations

6 Provide seed funding and mentorship for community groups to work in partnership with health and social care, to develop, deliver and evaluate impact of localised compassionate communities initiatives

It is essential that mentorship and funding are easily accessible to individuals and community groups, to develop and implement initiatives based on their lived experience and in response to community need, and in partnership where appropriate with health and care services. A considered approach to the advertisement, application process and decision-making around allocation of support is needed. There is need to remove barriers for grass-roots initiatives to apply for funding. Overall, funding eligibility should be contingent on demonstration of close partnership working with community members. Appropriate funding and mentorship are needed to facilitate robust evaluation of impact, which may then maximise knowledge transfer by helping us to understanding which approaches work for whom, and in which circumstances. In the Republic of Ireland, this funding and mentorship could be facilitated through competitive applications to the Sláintecare Healthy Communities Programme, as referenced in the new National Adult Palliative Care Policy (2024).

7 Support the development of compassionate communities of practice, to share and to mobilise learning from existing compassionate communities initiatives

There is a need to retain and mobilise the lessons learned from existing compassionate communities initiatives. Through establishing compassionate communities of practice which are placed-based or aligned to specific populations or needs, opportunities for collective learning, networking and problem-solving will help to refine work that is already going on, sustain initiatives, and inspire future work. This will also be necessary to support collaborative engagement across the island of Ireland.

8 Establish steering groups for the development and delivery of compassionate civic charters in council areas both North/South

There is a need to promote civic policies and practices for supportive care inside all civic sectors- from workplaces, schools, or faith groups to social clubs, cultural centres and neighbourhoods. The establishment of steering groups- led by local councils in partnership with leaders from across civic society and community members- should develop and deliver on tailored compassionate civic charters reflecting the needs of their locality. Government departments should also look for opportunities to work together on a regional basis to deliver larger programmes of work, for example delivering on the recommendations within the 'Compassionate School Communities' report and initiating similar work in other key sectors. Developing and delivering on a compassionate civic charter will ensure the systems level change needed across all sectors of society.

9 Commission research to support a 'roadmap' for fostering compassionate communities across the island of Ireland, focused on understanding local need, understanding what has worked for whom, where, and in what circumstances, and embedding best practice

There is a need to ensure the development of compassionate communities across the island of Ireland is informed by a robust evidence base of community-engaged research. Research supporting compassionate communities will allow for a more thorough understanding of the development, impact and sustainability of initiatives within our context, and will help ensure learning both regionally and internationally is reflected in practice.

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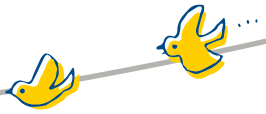

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