Health Inquiry Committee
Compassionate Communities NI
5 June 2025

Attendees: Sharon Williams, CCNI, Fiona Gilmour, NHSCT and Thelma Abernethy, Cruse Bereavement Support

Firstly, thank you for carrying out this inquiry. We appreciate the opportunity to give this presentation today, to supplement our written submission. Today, we want to speak openly and honestly about a difficult truth: palliative care services in Northern Ireland are not meeting the needs of our people. We're here to share what our experience, to amplify the voices we've heard, and to explore how, together, we can do better.

Too many people are denied equitable access to palliative care, which is a fundamental human right, leading to needless suffering of patients and families. This service gap echoes across the system, intensifying pressure on emergency services, creating operational inefficiencies, and undermining workforce wellbeing.

For the purpose of today we want to address 3 key areas:

1. **Public perception of palliative care services**
2. **Fragmentation of services**
3. **Whole systems approach solution**

Firstly, public perception of palliative care services.
We want to impress on you the need for a public health approach to palliative care, one that addresses public awareness and education, and requires a whole system approach to care.

The Compassionate Communities international movement is a public health approach focused on improving palliative and end-of-life care within communities. Compassionate communities care and support people where they live, work, learn, pray and play. It emphasises a shared responsibility for care. Collaboration between local residents, organisations, and healthcare services are seen as critical to enabling support for individuals and families facing serious illness, death, and bereavement.

A 2025 position paper '*Fostering Compassionate Communities: A Call to Transform Caregiving, Dying, Death and Grieving on the Island of Ireland'* advocates for a coordinated, island-wide compassionate communities' response. This report by Queen's University produced in consultation with the public, and people from community and statutory sectors recognise that North and South of the border share challenges around death and bereavement. North–South collaboration has begun aligning processes in areas such as advance care planning (ACP) however further concerted support and action is needed.

Ensuring equitable access to quality palliative care is not the sole responsibility of the Department of Health; it is everyone's responsibility. Dying is not just biological; it is a significant social event that is inevitable for us all.

As a society, with the medicalisation of dying and death; we have lost the meaning in 'normal dying', when death is expected, because it largely happens behind closed doors in hospital. Whilst

it is appropriate that some of these deaths happen in hospital, more could be done to enable this to happen in the person's home, if that's their preference.

A person cannot be viewed simply as an illness; cancer doesn't just affect an organ the same, as dementia doesn't simply impair cognitive ability. Advanced illness impacts every facet of the person's wellbeing, such as physical, emotional, social and spiritual. We need to be cognisant that this also affects the people important to the person who is ill. Carer burden and burnout is well documented, and we know that Carers NI spoke to this a number of weeks ago.

Added to this, practical issues such as financial hardship are common. Examples include, the loss of a household income, travel to appointments, time off work, the cost of running medical apparatus at home and keeping warm.

People report feelings of loneliness and social isolation as they may need to withdraw from the workplace, lose their mobility and independence or may lose their role at home. Sadly, friends and family may stop calling, as they think they are busy with medical appointments and don't want to intrude or simply can't cope with the illness and pending death.

Prof. Allan Kellehear, founder of the compassionate communities' movement, references the 95% rule. The assumption held by communities is that a person living with advanced illness or frailty spends 95% of their time with healthcare professionals. Conversely, they typically spend only 5% receiving treatment and 95% of their time is living in their communities, in their home. The ageing population in Northern Ireland is increasing with many living alone with only their radio, TV or maybe a pet for company. Loneliness and social isolation are known to be as detrimental to health as smoking 15 cigarettes a day.

Secondly, we want to impress on you the impact of accessing care and support in a fragmented palliative care system.
Navigating a complex system at a time of crisis further compounds an already overwhelming situation. The person who is ill or the family often feel alone and wonder how they are going to cope.

- They don't understand the difference between generalist and specialist palliative care services, nor do they understand where to contact these services.
- Many people in community don't know the District Nurse is their 'palliative care key worker' and what they can offer.
- Nor do they know, who to contact out of hours – or if help will be available.

This complex siloed system often results in poor communication between service providers and patients. Sadly, as a result of this, person-centred care is compromised and there may not be timely access to appropriate care. This in turn can cause increased anxiety and frustration with the system.

Added to this there is an extra layer of complexity for people living:
- in rural communities
- with intellectual disability or severe mental illness
- seldom heard communities

To help us understand the scale of need we can apply a simple equation:
- The total population in NI stands at around 2 million.

- We know that approximately 1% of the population dies each year, so around 20,000 people will die in 2025.
- Referencing Marie Curie's research, it is estimated that 1 in 4 people who would benefit from palliative care will not receive it.
- Therefore, it can be deduced that 5,000 people this year will potentially miss the opportunity of holistic care, including symptom management, improving quality of life and a good death. This experience is likely to have a significant impact on the wellbeing of family and carers.

It is critical that the family's mental, physical and spiritual needs are supported throughout the palliative and end of life care journey. Cruse estimates that 6 people are significantly impacted by a death. Therefore, it is likely that in 2025 around 120,000 people will be impacted by bereavement. The majority of these people are likely to be supported in their communities, and some will require professional support.

Public understanding of palliative care and bereavement remains low and although awareness is slowly improving, many still equate palliative care with cancer or dying. The consequence is that people living with other life-limiting illnesses such as COPD, dementia, or heart failure, whose quality of life may have been improved earlier in their illness, sometimes only access palliative care service at the very end of their life.

Some people are reluctant to accept palliative care, as they have misconceptions, for example,
- the syringe driver is perceived as a form of euthanasia
- palliative care means all active treatment will stop
- a reluctance to start morphine for pain management for fear of becoming addicted.

Aimed at improving health and death literacy one important initiative is the development of 12 Death Positive Libraries in Northern Ireland. They host resources on dying, death and bereavement, which includes easy read and children's books. This initiative is reliant on charitable funds and requires mainstream funding.

There also exist significant gaps in bereavement education and awareness across many sectors. Marie Curie's report "Compassionate School Communities" highlights the profound impact that bereavement can have on young people. It reveals that 78% of school leavers who have experienced loss struggle academically, face challenges with their mental health, and may exhibit worrying behaviours. Creating environments that guide children through palliative care, dying, death and bereavement is essential for nurturing resilience in future generations whilst protecting teachers' wellbeing.

National Lottery has funded Cruse to develop a range of evidenced-based interventions on bereavement for children and young people, which they deliver within schools and community settings. It is critical this work is mainstreamed for funding.

Recently the Northern Trust has established a Compassionate Schools Working Group to bring together all key stakeholders to explore this work further.

Marie Curie reports that 73% of people in NI are unfamiliar with the term advance care planning. To help address this, Compassionate Communities has been delivering advance care planning events in communities for 3 years. We are aware that healthcare professionals have highlighted the clinical component previously, yet nearly 3 years on, the NI Advance Care Planning Policy for Adults has yet to be implemented alongside RESPeCT.

It's our experience that people often worry about the financial and legal components of advance care planning. Complex legal terminology and confusion between different jurisdictions is a real barrier to people putting their affairs in order, such as writing their will and appointing their power of attorney.

There is of course, the reluctance to engage with this taboo subject. However, we find that given the opportunity to talk about end of life, through creative engagement, people find their voice and the chance of working through challenging emotions.

But some people are proactive, CCNI regularly receive requests for information. We have delivered numerous sessions, some examples include for people living with dementia, Parkinson's and MS; frontline staff in homeless community and healthcare professionals.

It's imperative to embed advance care planning discussions into everyday life before a health crisis hits.

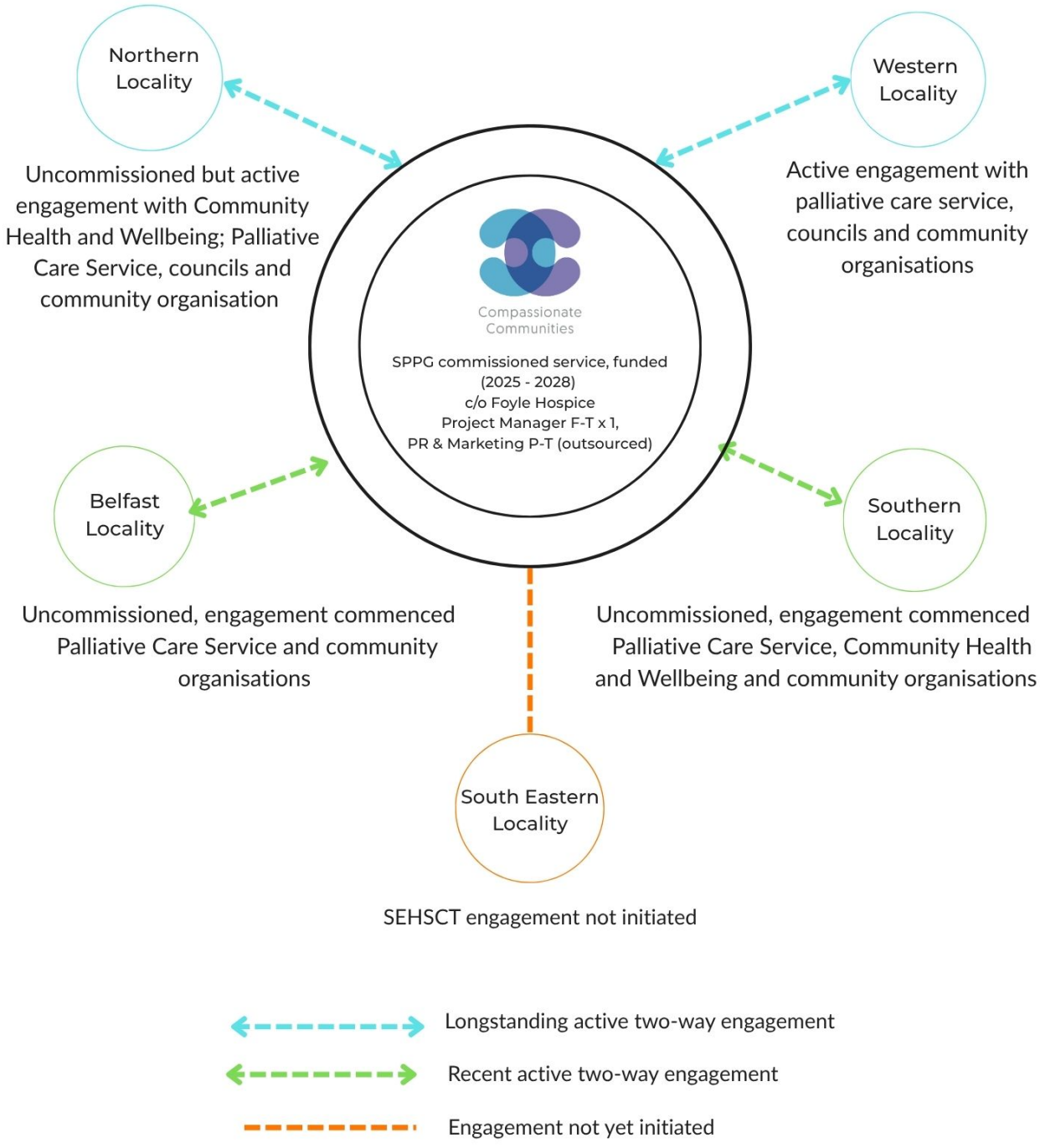
Thirdly, we are hopeful through a whole system approach there will be a solution.
Action and accountability are needed, to implement recommendations in pre-existing and relevant reports, to meet current and future need. To achieve this, we recommend the following:

1. A public health approach to palliative care that delivers coordinated regional/ all island awareness campaigns.
2. Sustained investment in community organisations and support for unpaid carers, recognising them as essential providers of palliative care and bereavement support.
3. Adopt the Compassionate Civic Charter as part of the wider palliative care support infrastructure that provides public leadership, shared accountability and co-production.
4. Facilitate a regional compassionate communities programme that enables the development of compassionate communities' hubs in each Trust area.
5. Palliative care and bereavement services are prioritised and funded as an integral part of population health and wellbeing.
6. A whole system approach that is governed and mandated by a regional Palliative Care Strategy.
7. Improved integration between government departments
8. Full implementation of Advance Care Planning that invests in public education.

We are hopeful that as a result of this inquiry, available measures can be immediately implemented and that a long-term strategy can develop a more equitable access to palliative care for everyone.

In conclusion, we want to restate that individually and collectively we are responsible for ensuring that expected deaths are experienced as '*good deaths'*. Just as it takes a village to raise a child, it takes a community to care for the dying.

Compassionate Communities NI Regional Engagement and Resourcing June 2025



Together we are better and stronger