Compassionate Communities Northern Ireland

Are you a healthcare professional?

No

What is your interest in PC services

Compassionate Communities NI uses a public health approach to palliative and end of life care. There are 2 hubs, one based in the WHSCT (c/o Foyle Hospice) which is 100% funded by SPPG and one based in the NHSCT, where the related work is uncommissioned but undertaken by staff who appreciate the importance and value of a public health approach. The team is a blend of clinical and community development professionals who joined forces in 2020. Through partnership work we combine skills, experiences, and financial resources to raise awareness and co-develop resources that aim to inform, educate and empower self-directed support and support for each other.

We advocate for improved experiences of dying, death and bereavement for the people of Northern Ireland through improved health and death literacy, increased death preparedness and increased community capacity to support people during a health crisis. We acknowledge that compassion has the power to influences health outside the healthcare system but because, in-part, of the over-medicalisation of normal dying, as a society we have lost the learning death and lack the confidence to offer emotional and practical support.

CURRENT STATE OF PALLIATIVE CARE SERVICES

In your view what is the current state of palliative care services in Northern Ireland?

Neither

Do you think there is an understanding by the public of what palliative care is? If no, what are the main barriers to the public understanding palliative care?
Results from the Northern Ireland Life and Time Survey indicates that awareness and understanding is improving however the misnomer that palliative care means end of life persists. There is greater understanding that palliative care is available for diseases other than cancer but the distinction between generalist and specialist palliative care and who delivers this care is not greatly understood. The complex and non-standardised palliative care system in NI is partly a barrier to the publics' understanding.

Death is a taboo topic and creates a societal barrier to talking about dying, death and bereavement. Reluctance to engage in conversations is often rooted in feelings of overwhelm and high emotion both of which can be mitigated with education and support and help to move people to empowerment and resilience. As a result, there

are differing degrees of understanding and support which leaves people living with advanced illness, frailty, caregivers and people living bereavement feeling socially isolated and lonely.

Education, support and opportunities to open conversations need to be enabled in the places where we live, work, learn, play and pray. Enablement would ensure that teachers training includes a bereavement module, school curriculum includes education on death and bereavement, employers have compassionate policies that can respond to employee needs as they undertake caregiving roles, work while living with advanced illness and are supported during a period of bereavement. Creative engagement through the arts would offer a variety of mediums in which people can look to understand and heal.

ACCESS TO SERVICES

Are palliative care services equally accessible to all who need them?

No

From your experience where are the gaps in the provision of service?

Patient and family experiences of palliative care services in NI vary greatly, some access excellent care and support but regrettably this is not the experience of others. This variation is largely due of the lack of integration between care providers in acute settings, hospices, care homes and between generalist and specialist palliative care. The complex system presents an overwhelming experience for people who are at a point of crisis. It is not uncommon for a patient to be discharged from a curative treatment setting to palliative care with little insight into the patient pathway, patients and their carers report that they feel like they ‘fall off a cliff’. Services and information on the patient’s pathway are not standardised across the region and results in a type of postcode lottery.

Gaps in provision are evident in the homeless and prison communities. The demands of an ageing population in these communities’ places additional burden on frontline staff, for example prison guards report that they feel like nurses as mobility issues of their 50+ population reduces independence.

Staff from trusts and the community and voluntary sector supporting the homeless community are trying to manage the complexities of comorbidities and the psychological impact that a general decline in health has on the individual and on support staff. CCNI has provided staff training on advance care planning and compassionate conversations to support staff so that they feel more prepared to help their clients and build in selfcare to protect their own wellbeing.

Frailer older people living in rural areas are often living alone with a general decline in health. Access to community services is compromised as a limited number of community palliative care nurses juggle large patient caseloads covering a large geographical area. Community and voluntary groups do what they can to support

people impacted by loneliness and isolation through daily calls and befriending schemes. Again, CCNI has provided training in the palliative care approach and advance care planning which support and expand service provision and protect staff from burnout. The community and voluntary support are a lifeline, but the funding model often does not support long term sustainability and has significant impact on staff wellbeing and retention.

Do you believe barriers exist that prevent equitable access to these services?
Yes

If yes please provide examples on the box provided

- The absence of a regional approach and Palliative Care Strategy
- Inadequate integration of services across sectors and government departments Incomplete implementation the of advance care planning policy
- Lack of investment in public health campaign and public education
- Inappropriate funding model to develop and sustain services in the community and voluntary sector
- Lack of training for:
    - Health and social care staff
    - Community staff
    - Carers

What additional services could/should be provided

A recent Marie Curie evidence paper, 'Delivering the Best End of Life Experience for All' https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/delivering-the-best-end-of-life-experience-for-all-evidence-paper-on-place-of□death-trends-and-issues-in-northern-ireland-to-2040.pdf suggests a 74% increase in home and care home deaths because of an ageing population; increased investment in community care is required. A reimagining of how statutory providers can work collaboratively with partners in the community and voluntary and independent sectors to design and fund long-term solutions that address local needs. Scoping out what already exists may present opportunities to spread and scale good practice.

INTEGRATION OF SERVICES

How well are palliative care services integrated across the system, through primary, secondary and specialist care?

Inadequate integration of services within a complex palliative care system often results in patients falling through the gaps. The reality is that patients receive palliative care so far down the disease trajectory that they are end of life. Sadly, research conducted by Marie Curie estimates that 25% of people who would benefit from palliative care do not receive it.

Endings matter, they matter for the person who is dying and for those they leave behind. A bad death traumatises those who witness it with the potential for complicated grief health Social care professionals providing care are also impacted by experiences of a bad death.

Should palliative care be a regional service? Please outline your reasons in the box provided.

Palliative care should be a regional service that benchmarks a standard of care accessible to all that allows for differences in communities. The needs of a rural community for example are different from the needs of an urban community where public transport is more accessible and where there is closer proximity to healthcare services.

What can be done to improve integration?

A whole system approach is required to ensure a compassionate infrastructure that supports a health and social care system that has capacity and works in partnership with community actors and the public.

BEST PRACTICE

Do you have any examples of good practice or pilots in palliative care that are meeting the needs of patients and families/carers? If so, is this best practice happening widely.

Compassionate Communities is a collaborative initiative between statutory bodies and the community and voluntary sector, adopting a public health approach to palliative care. This partnership has supported the creation of a regionwide website, http://www.compassionatecommunitiesni.com/, and the development of a range of multimedia resources and educational workshops aimed at increasing public awareness and engagement with end-of-life planning and support.

Examples of CCNI's integration and partnership delivery:

- Compassionate Communities Northern Steering Group consists of 16 members from NHSCT Health and Wellbeing, Palliative Care and Bereavement; NI Hospice, Cruse, Mid and East Antrim Agewell Partnership, Marie Curie, Alzheimer's Society, Citizens Advice, Age NI, PHA, Healthy Living Centre, Lived Experience, Antrim and Newtownabbey District Council, Mid Ulster District Council and Rural Support. Work collectively to share best practice and work in partnership on awareness and education initiatives.

- Death Positive Libraries https://www.compassionatecommunitiesni.com/death-positive-libraries partnership between CCNI, NHSCT, Libraries NI and Cruse to provide resources, host events, and facilitate discussions that aim to empower the public to approach the topic of death with curiosity, respect, and compassion. Currently there are 12 locations in NI and 3 in ROI (though the Art of Life project).

- Connected Compassionate Communities, a community of practice providing a forum for support, education and practice development for members passionate about improving the experiences of death, dying and bereavement for people in Northern Ireland.

- Compassionate schools, a partnership between NHSCT, Cruse, CCNI and Mid Ulster District Council working with schools to improve awareness and education within schools.

- Further to a national conference held during Palliative Care Week 2024, a position paper, 'Fostering Compassionate Communities: A call to transform Caregiving, Dying, Death and Grieving on the island of Ireland' (https://aiihpc.org/wp-content/uploads/2025/01/Compassionate-Communities-Position-Paper-2025.pdf), was produced by Lisa Graham-Weisner and her team at Queen's University. A steering committee with members from the All Ireland Institute of Hospice Palliative Care, Compassionate Communities NI and the Irish hospice Foundation are currently working to progress the nine recommendations.

- Cross-border advance care planning project the 'Art of Life' https://www.compassionatecommunitiesni.com/the-art-of-life-projectusing the arts to normalise conversations around dying, death and bereavement and enable advance care planning. Partners include CCNI, Cavan County Council, Irish Hospice Foundation, Compassionate Communities, Cavan Age Friendly, South West Age Partnership, Healthy Ireland, Libraries NI.

- Partnership between CCNI and Derry City Strabane District Council to develop a Plan Ahead page https://www.derrystrabane.com/community/age-friendly/planaheadon the council's website increasing visibility of advance care planning and access to resources.

- Mid Ulster Loneliness Network https://www.compassionatecommunitiesni.com/post/health-wellbeing-get-together-in-aughnacloy a cross sector partnership that provides a co-ordinated and consistent approach to preventing and addressing loneliness in the Mid Ulster area across the generations.

  Other examples of good practice include:
  The Palliative Care in Partnership Board has already established regional networks and forums to address improved integration, a public health approach and a regional framework for Palliative and End of Life Care Education and training.

Co-creating hope for Fermanagh and Omagh, a working group bringing together statutory and community sectors to develop innovative solutions to address the needs of isolated frail people in the area.

Just in case boxes, piloted in the WHSCT, ensures that patients have medications to hand that can be administered by a District Nurse/GP when needed. This initiative eases carers concerns and helps to maintain people at home.

Are these practices available widely? No, but many are working towards spreading and scaling. However, obstacles which include the absence of a regional approach, workforce capacity, lack of funding and sustainability, long-term vision and integration between sectors results in localised pockets of action.

Do you think that families receive sufficient support when accessing services? Please outline your reasons in the box provided.
No.

Families often struggle to obtain timely access to essential information and services. Key areas requiring enhancement include:

- **Carer support**—both practical assistance and respite
- **Complementary therapies** to manage symptoms and reduce stress
- **Financial guidance and assistance** to navigate benefit entitlements and plan for end of life
- **Bereavement care**, both before and after a loss, but also general education on the bereavement journey

To address these gaps, we recommend strengthening partnerships between statutory bodies and the community/voluntary sector. By developing place-based care solutions underpinned by secure, long-term funding, we can build a more resilient and sustainable infrastructure for community-based palliative care.

FUNDING AND STRATEGY

Do you think the current funding for palliative care is sufficient? Please outline your reasons in the box provided.
No.

Compassionate Communities NI believes palliative care in NI is underfunded and has lacked investment over many years. However, efficiencies may be available with current funding. A 2025 Nuffield Trust and the Health Economics Unit, commissioned by Marie Curie https://www.nuffieldtrust.org.uk/news-item/over-80-of-healthcare-cost-in-the-final-year-of-life-spent-on-hospitals reveals that the UK spends approximately £22 billion annually on individuals in their final year of life. Of this, £11.7 billion (53%) is allocated to healthcare, with hospital care

consuming 81% (£9.6 billion) of these costs. Emergency hospital services alone account for £6.6 billion. In contrast, only 11% (£1.3 billion) is spent on primary and community healthcare, and less than 4% (£414 million) on hospice care. The report highlights a significant imbalance in end-of-life care funding, emphasising the need to shift resources towards community-based services to better align with patient preferences and improve care quality.

Is the current model for the funding of hospices, including hospice at home/community care/rapid response support, sustainable and sufficient to meet needs now and in the future? Please outline your reasons in the box provided.
No.

Hospices presently face a 60% funding shortfall, forcing them to depend on alternative income streams such as charitable donations and fundraising. In the Republic of Ireland, by contrast, hospices receive full statutory funding. It is concerning that a healthcare system committed to supporting individuals throughout their lifespan underfunds its palliative and end-of-life services, despite end of life being an integral part of life itself.

With an ageing population, demand for palliative care is set to increase substantially. If the current funding model cannot meet needs today, it is difficult to envisage how it will cope in the future. This gap in provision affects not only the patients we serve but also each of us, as we and our loved ones will one day rely on these very services.

Is there a need for a new Palliative Care Strategy for Northern Ireland? If yes, what should it include? If no, why not? Please outline your reasons in the box provided.
Yes.

A comprehensive, forward-looking Palliative Care Strategy for Northern Ireland is essential to align services with demographic realities, reduce hospital dependence, secure sustainable funding, and deliver person-centred care in the community. Without a strategy, both providers and patients will face mounting pressures and uneven access to quality end-of-life support.

Any other comments
We welcome the Health Committee's thorough review of access to palliative care. Assessing current challenges and reinforcing existing strengths is an essential first step toward transforming palliative care across Northern Ireland. It is also vital to recognise that ensuring a dignified, "good death" is a shared responsibility for us all.