



Grief & Bereavement in Northern Ireland

May 2022

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Summary of Engagement

Introduction

In Scotland and the Republic of Ireland, Bereavement Charters have been produced, by Cruse Bereavement Care Scotland and the Irish Hospice Foundation respectively. The PCC are, in partnership with members of the public, members of the NI Bereavement Network and representatives from the statutory, voluntary and community sectors, working on the development of a Bereavement Charter for Northern Ireland. This paper presents a summary overview of **what we have heard** through this engagement work to date. This will serve as the foundation for draft Charter statements.

Intention for Charter

Bereavement charters are seen in Scotland and the Republic of Ireland, as supporting the provision of the right care and support at the right time, which promotes a more holistic system-wide approach and attitude towards grief and bereavement, death and dying. The intention for a Bereavement Charter in Northern Ireland is that it will underpin the following aims:

1. Bereaved people will be treated with understanding, empathy and compassion
2. Promote open and frank conversation around death and dying, grief and bereavement.
3. To encourage the population of Northern Ireland to consider Advance Care Planning before the end of life/palliative care stages.
4. For clinicians, public serving bodies, and those providing bereavement services, to work in tandem and ensure a high standard of service provision and information availability for the population of Northern Ireland.
5. Give consideration to the policy forces in Northern Ireland and bring to focus their goals of promoting health, wellbeing and empowerment.

Background

The Department of Health developed and finalised the report “COVID-19 Guidance: Bereavement Advice and Support” in 2021. One of the key recommendations from this report was:

“That the HSC Bereavement Network membership is expanded to become the Northern Ireland Bereavement Network, with responsibility for developing and leading the strategic bereavement plan for the next 10 years. The Northern Ireland

Bereavement Network should include all relevant cross-departmental and community organisations and agencies”

As a first stage in this work, the Patient and Client Council (PCC) are taking forward in partnership; work on the development of a Bereavement Charter for NI as part of the NI Bereavement Network. A Bereavement Charter sets out pledges to bereaved individuals and loved ones about the standards of service and care they should expect to receive following the death of a loved one.

Engagement Platform

An Engagement Platform with a focus on Bereavement in Northern Ireland was established by the PCC in November 2021. Its purpose was to be a centralised conduit for engagement with a focus on the broad theme of Death, Dying, Grief and Bereavement, with the development of a Charter as a first step in this work. The platform allowed interested parties to come together and discuss bereavement with a view to informing decision-making on a departmental level in relation to bereavement and bereavement support. It also encourages learning, interaction and a partnership approach amongst the public, clinicians, service users, and other bereavement service providers.

The Engagement Platform membership is made up of members of the public, representatives of the community and voluntary sector, and others with an interest in bereavement. These include:

- Individuals with lived experience of bereavement
- Carers and families of those with lived experience of bereavement
- Advocacy and lobbying organisations;
- Community and voluntary sector;
- Individuals and collectives of the public who have an interest in Bereavement, Health and Social Care and arm's length bodies (ALBs)

Six sessions of the engagement platform have been held to date between November 2021 and March 2022. Participants have talked about defining what bereavement means to them and what a bereavement charter should look like - what format it should take and what its foundation, function and role should be. The engagement platform has also drafted a survey around death, bereavement and grief in order to engage the views of the broader public that would contribute to a Bereavement Charter for Northern Ireland.

What we heard

Members were generous with their time and participation which led to rich and in-depth discussion around what bereavement meant to them. Members talked about their **personal experiences of loss, the lead up to a death or shock of a death, the grief process, and the grief of a life the person could have lived**. Whilst there are similarities in how people experience grief and bereavement, each loss is unique to person, and can depend on who died and how they died.

- *“It’s so unique, it depends on you as a person and the resources and support available around you. It’s a change – financially, emotionally, and planning for the future.”*

They talked about **anticipatory grief** in the lead up to a loved one’s death. Members spoke of the **fear, worry, anxiety and guilt they felt before a death**. Some spoke of the **lack of support they had available** to them and their families before a death.

- *“It’s not just grief, but fear coming up to that loss, or guilt too that someone will die and there’s nothing you can do in the run up to the loss.”*
- *“the anticipatory loss is one is full of worry, anxiety and fear ... I wasn’t expecting the amount of fear, the paralysis, lack of sleep and panic attacks which went on for 6 months after the death.”*

Members also spoke about **how society often does not value all deaths**. They discussed that often certain deaths, such as suicide or from substance abuse have stigmas attached to them. They also spoke about a **‘hierarchy of deaths’ that society viewed some deaths as lesser than others as they “chose” or “took a risk”**. The group felt that it is important that **all losses and their grief and bereavement to be valued, no matter what the circumstances** of their loved ones death. They felt this should be reflected in a Bereavement Charter.

- *“When there’s been a loss the additional stigma attached to the circumstances of the loss is hard.”*
- *“Every bereavement counts they are all a loss”*
- *“It’s not a champions league of losses. If we can find a way to say that everyone’s life mattered no matter what the circumstances of their death. It’s shocking in 2021 we shouldn’t have these stigmas.”*
- *“It’s about the tragedy of the life lost not what brought them there.”*

There was also discussion of **the impact of the Covid-19 pandemic on grief and bereavement**. Members spoke about how the rules meant they could not have traditional funeral arrangements and gatherings. In addition members spoke about how due to the pandemic and restrictions they were unable to be there at the end of their loved ones life too.

- *“The rules were barbaric and harmful. It was isolating and left me with a lot of anger.”*
- *“The ability to be with them and support them as I had before Covid was gone.”*
- *“We missed the opportunity of being able to physically touch the people we are close to. That was taken away during covid.”*
- *“Due to Covid families haven’t been involved as much as they would have been ... We don’t have wakes and people haven’t had their ‘normal’ bereavement process.”*

The group also spoke about disenfranchised grief, how people’s grief doesn’t always fit into what society thinks of loss. One member who is transgender spoke of how their family grieved the loss of the person they once thought they were and how many people were unable to accept who they are now.

- *“They are grieving my loss, but there was never a body to grieve.”*

It was agreed that a Bereavement Charter for Northern Ireland needed to be wide ranging. It was acknowledged that the Charter could not encompass every grief but it could attempt to be as inclusive as possible. There was also discussion over finding the balance between a rights- based and values-based Charter. It was concluded that they complemented one another and went hand-in-hand, driving one another.

Survey Findings

To help initiate the wider societal conversation needed for the development of a Bereavement Charter for NI, the PCC ran a survey, co-designed by the Engagement Platform, to understand what matters most to the people of Northern Ireland when considering death, bereavement and grief. The questions asked can be seen in [appendix one](#). There were five open-ended questions in this survey. We encouraged respondents to be as open and frank as possible in their responses to the survey to ensure that charter development was as representative of our society and the communities within it as possible. A survey was launched 22nd December and closed 7th February 2022. There were **230** respondents to the survey.

Of the 230 respondents, 55% (n=126/230) expressed that bereaved people **needed access to support throughout their grief**. This support included counselling, practical support, financial support and guidance as well as being supported by friends and family. A smaller proportion, 3.5% (n=8/230), of respondents expressed that they wanted this support to be **tailored to their needs**. A few (4) mentioned that there needed to be **specific support** put in place **for children**.

Furthermore, 6% (n=14/230) of respondents stated that this support needed to be **long term**. They also said that support needed to be **timely**; 21% (n=49/230), they would like to speak to someone when they need supported, as they might not seek

support when person dies, but weeks, months, or years after. In addition, they wanted this **access to be timely** and not subject to a lengthy waiting list to access services like counselling and peer support networks.

Some respondents, 7% (n=17/230), spoke about the **desire to be signposted** to organisations that could help them. This included organisations that could answer queries on funeral arrangements, registering a death, compassionate leave entitlement and what support groups existed.

A fifth of respondents, 20% (n=47/230), said that they needed **time to grieve**. Respondents said they needed time to be away from work and to recover from the death of a loved one. A number of these people mentioned that they needed to not feel pressured into going back to school or work. It was also expressed that everyone's circumstances are different and so how they grieve and how long they grieve is different too. They spoke about having a period to mourn and reflect - coming for help and support in their own time and not feeling they needed to 'rush through the process' as there is no linear pattern to grief.

Just under a third, 30% (n=70/230), said that we **needed to be more open** about death and dying. Respondents raised issues about the need for people to **make known their wishes** for their funeral, burial and how they would like to be remembered, as well as putting in place practical plans and provisions for your loved ones. Furthermore, 9% (n=21/230) of respondents said that we **needed to talk more about loss**.

Many respondents said that the deceased person needed to be treated with dignity and respect, including the need to be non-judgemental and respect a loss and loved ones grief no matter how the death occurred.

Both the Engagement Platforms and Survey mentioned the **desire for 'normal' funeral arrangements as the pandemic restrictions eased**. These respondents spoke about how hard Covid-19 had made the grieving process and spoke about the **absence of traditional forms of mourning**, such as not having a wake, not being able to console a bereaved person, or not being able to attend a funeral service.

A smaller number of people said that they felt it was not possible to have good grief and **did not like the phrase 'good grief'**. They said it would be hard to have good grief in a sudden death, and that a loss can be painful no matter what the circumstances.

Conclusion

There were several key themes emerging from engagement on the topic of death, dying, grief and bereavement across the Engagement Platform meetings and wider public survey:

- The need for more support services & better signposting to organisations that can help them as they grieve
- Every death needs to be valued regardless of the circumstances of the death. It was expressed that there should not be a '*hierarchy of deaths*' and that people should be non-judgemental in their respect for loss and loved ones' grief.
- As a society we need to be more open about death and dying
- People need space and time to grieve. People feel there is often a pressure to return to work too soon. Each grief is unique, and that people's grief journey is not linear. How a person grieves and how long they grieve varies from person to person.
- The impact of Covid-19 restrictions on mourning and funerals - being unable to be there with loved ones and go through the 'ritual' of wakes, funerals etc which can have an impact on the mourning process.

Next Steps

The PCC will share this summary paper with members of the Engagement Platform and the NI Bereavement Network. It will be used as a foundation to draft initial Charter statements and to inform ongoing work of the NI Bereavement Network.

Appendix 1 – Survey

Grief & Bereavement in Northern Ireland

The Department of Health developed and finalised the report “COVID-19 Guidance: Bereavement Advice and Support” in 2021. One of the key recommendations from this report was:

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As a first stage in this work, the Patient and Client Council (PCC) are taking forward in partnership, work on the development of a Bereavement Charter for NI as part of the NI Bereavement Network.

A Bereavement Charter sets out pledges to bereaved individuals and loved ones about the standards of service and care they should expect to receive following the death of a loved one.

To help us to begin the wider societal conversation needed for the development of a Bereavement Charter for NI, the PCC are running the following survey to understand what matters most to the people of Northern Ireland when considering death, bereavement and grief. This survey encompasses all experiences and is not limited to life-limiting conditions or expected deaths.

There are five open-ended questions in this survey. We would encourage you to be as open and honest as possible in your responses to this survey, all of which will be anonymised. This will ensure that charter development is more representative of our society and the communities within it.

1. If we are to value all people then we must value all death, regardless of type or circumstance of death. To do this we must...

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2. When I think about death, bereavement and grief what matters to me is...

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3. In my community we could deal with death, bereavement and grief better by...

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4. To experience “good grief” I need...

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5. When I think about grief and bereavement, the support that I would like is...

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