

# Terminal illness and bereavement during the Covid-19 pandemic in Northern Ireland



Care and support through terminal illness

Perspectives of those left behind and lessons for the future

**Patient and Client Council**  
Your voice in health and social care





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## Introduction: the Covid-19 pandemic – a mass bereavement event

The period since March 2020 has correctly been described as a global health pandemic – but it could equally be framed as a mass bereavement event.

Hundreds of thousands of excess deaths have been recorded across the globe, and Northern Ireland has not been immune from this trend.

During the period between the end of March 2020, when the first lockdown restrictions were introduced, and March 2021, nearly 18,500 deaths were recorded in Northern Ireland – a 15% rise on the five-year average.<sup>1</sup>

Importantly, Covid-19 accounted for less than one-fifth of these deaths, which serves as a crucial reminder that, throughout the pandemic period, people have still been living and dying with other chronic and life-limiting illnesses.

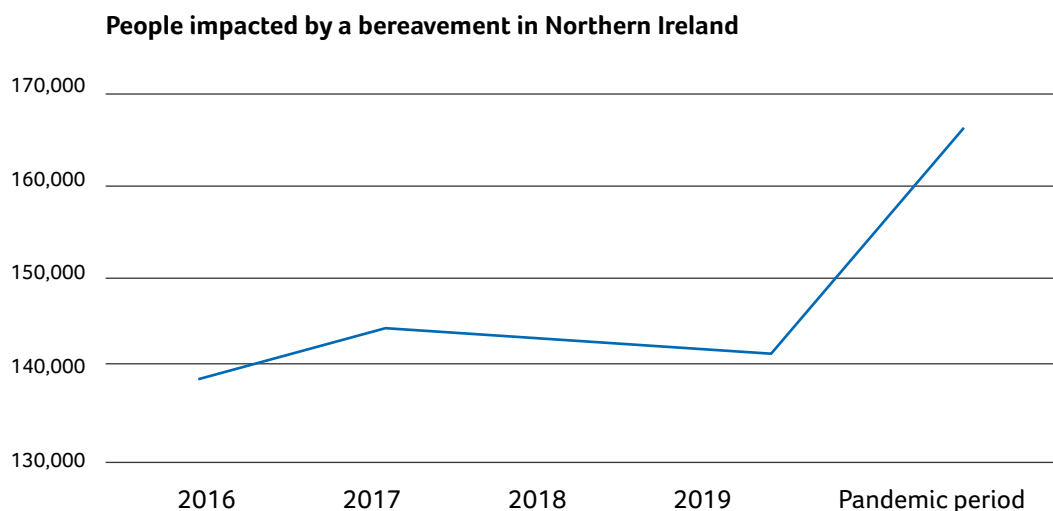
The data available at the time of writing is limited, but we know that over a quarter of

all deaths in Northern Ireland in 2020 were caused by cancer. Heart disease and non-Covid respiratory diseases – which include conditions like COPD – contributed close to another fifth (9% and 10% respectively).

It is also worth remembering that many Covid-19-related deaths were among people with pre-existing chronic conditions – for example, in 32% of these deaths between March–December 2020, the person also had dementia or Alzheimer’s disease.<sup>2</sup>

All in all, we estimate that over 166,000 people in Northern Ireland were impacted by a bereavement during the 12 months from March 2020–March 2021.<sup>3</sup> That represents one in 11 local people mourning the loss of a loved one.

In some way or another, the circumstances of the pandemic will have had an impact on every one of these deaths. From the delivery of care in hospital or the community, to final goodbyes, funeral rites



and bereavement support, the pandemic has torn up the rule book on death and dying in Northern Ireland. Covid-19 is a novel virus, and equally unique is the way it has impacted on the dying and bereavement processes.

This report seeks to explore these issues from the perspective of bereaved people in Northern Ireland. It looks at the impact of the pandemic on the care that terminally ill people received as they approached the end of their lives, and the experiences and support needs of those left behind.

The evidence laid out in the pages that follow was gathered through three workstreams:

- [A series of online focus groups with people bereaved during the Covid-19 pandemic in Northern Ireland. These focus groups were conducted by the Patient and Client Council and took place in January 2021.](#)
- [Qualitative data from 27 NI participants in a UK-wide survey on bereavement and Covid-19. The survey was conducted between August 2020 and January 2021 by Cardiff University and the University of Bristol.](#)<sup>4</sup>
- [Wider research on palliative and end of life care, bereavement and the impact of Covid-19 on these areas.](#)

Throughout the report, there are anonymised stories and reflections from people bereaved during the pandemic period; these have been gathered through these workstreams.

We hope this report will contribute to the growing body of literature that seeks to shine a light on the experiences of dying people and their loved ones during the Covid-19 pandemic. We do not claim that this report is an exhaustive account of this; only with the passage of time and further research will the full picture emerge.

We also think it is critical to take the lessons of the past 12 months and think about what we can learn for the future. The recommendations on pages 18-19 seek to do that.

### **Acknowledgements**

Thank you to everyone who shared their experiences with us in the focus groups and survey; to everyone who helped to disseminate the *Bereavement During Covid-19 Survey*; and to UK Research and Innovation (UKRI) via the Economic and Social Research Council (ESRC) for funding the study. Thanks also to the research teams at the Patient and Client Council, Cardiff University, the University of Bristol and their study collaborators and advisory group members across the UK.

## Access to palliative, end of life and wider health and social care services

**C**ovid-19 has caused one of the single largest disruptions in the history of the Health and Social Care (HSC) system in Northern Ireland. Services have been delayed, cancelled or moved online, while fear of the invisible threat – particularly in the early months of the pandemic – provoked a reluctance among many patients and their loved ones to engage with the services they normally rely on.

Like other groups, people impacted by terminal illnesses have been forced to adapt to this dramatically changing HSC environment.

### **Disruption and disengagement: care and support services in the Covid-19 context**

People who are terminally ill or deemed palliative receive care and support from a wide range of services – not just specialist palliative care providers, but GPs, District Nurses (see page 8), social care workers and more. These services and many others came under enormous pressure and were severely disrupted when the pandemic set in.

The impact on terminally ill people is highlighted in a Patient and Client Council survey of people who were shielding in Northern Ireland due to being clinically extremely vulnerable to Covid-19. Palliative patients reported disruption to their health and social care services and were concerned about deteriorations in their condition as a result – including loss of function or mobility.<sup>5</sup>

Further insight comes from two Carers NI surveys published in April and October 2020, both of which reported that 45% of carers in Northern Ireland were providing more care for their loved ones because local services had reduced or closed.<sup>6,7</sup> It is notable, and very concerning, that this trend did not improve over the six-month period between the two surveys.

On the other hand, many service providers also found that, even when their doors were open, some patients were reluctant to walk through them.

Settings like hospices saw a downturn in the number of people being admitted to their inpatient units – borne largely out of a fear of being cut off from family members because of Covid-related visiting restrictions.

There was a similar fear among patients, particularly in the early weeks and months of the pandemic, around letting health and social care staff into their homes in case they brought the virus with them. Like many others, community nursing teams providing palliative care were affected.

### **Communication when patients were in hospital**

Among those bereaved people who shared their experiences with us and whose loved ones had spent time, or died, in hospital, one of the challenges identified by some was communication.

In the context of restrictions on visiting, people described being unable to speak to their loved ones, struggling to get updates



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from the health professionals involved in their care, or being “drip fed” information.

***“No Zoom or Skype calls were offered and numerous phone calls were not returned. I can't stress enough how poor the communication channels were.”***

– Bereaved daughter (survey participant)

For some, this meant the limited information they received didn't always reflect the reality of their loved one's condition – leaving them unaware of how far they had deteriorated.

The impact of this situation can be severe, with poor communication and lack of understanding or awareness of the dying process linked to worse bereavement

outcomes among carers.<sup>8</sup> One focus group participant described being “haunted” by the things they couldn't do for their loved one before they died.

There was a near consensus among those bereaved people we spoke to that an identified single point of contact should be in place to communicate with family members and provide updates on their loved one's condition when they are in hospital.

***“One point of contact should be given to families for all communication. We found that no one had time to talk to us and we couldn't, despite asking, get a consultant's name.”*** – Bereaved daughter (survey participant)

It must be recognised that health and social care staff have been making Herculean efforts to continue delivering high-quality care in the face of unprecedented pressures and demand. Despite the challenges identified above, it was clear from some of the other bereaved people who shared their experiences with us that staff maintained good lines of communication, with incredibly positive results.

*“My mum and brother felt the doctors treated them with upmost compassion and explained the situation to them realistically but sensitively. They included them in discussions about his care wherever possible and showed a lot of compassion. We received a lovely card from the ICU team which was really personal... I will never forget receiving that card and it gave me even more assurance that my dad had been cared for by this team as if he were their own family, which was so important given that we could not be there with him.”*

– Bereaved daughter (survey participant)

### Care coordination

Pre-Covid-19, navigating the health and social care system and various palliative care services in Northern Ireland was incredibly challenging for some patients. Continuity of care was a problem for others.

Among the people we talked to for this report, some told us that their loved one’s care was very joined up, but others described a lack of coordination and felt there was a disconnect between services. These experiences underline the importance of Palliative Care Keyworkers.

Often performed by a District Nurse (DN), this role involves planning and co-ordinating care for patients with palliative care needs across services, teams and care settings. Palliative Care Keyworkers also help to ensure communication to maximise quality of life, promote continuity of care and, where possible, help the person to remain in their preferred place of care. <sup>9</sup>

Two challenges exist in this space. Independent of Covid-19, the District Nursing workforce in Northern Ireland has been under pressure, with high caseloads<sup>10</sup> and capacity issues impacting on DN teams.

District Nurses were also among the staff groups facing significant extra pressure when the pandemic began. As the Department of Health’s Strategic Framework for rebuilding HSC services stated in June 2020: “Demands on community teams has increased with





district nursing... supporting vulnerable clients in care homes.”<sup>11</sup>

Phase 3 of the Delivering Care programme – which aims to support the provision of high-quality, safe and effective nursing and midwifery care – focuses on District Nursing. Investment in the DN workforce is expected under Delivering Care. However, it is concerning that a report from the NI Audit Office in July 2020 reported a £38.8 million recurrent funding gap facing phases 2-5 of the programme.<sup>12</sup>

### Understanding of palliative care

A lack of understanding and awareness of what palliative care is has existed among the general public in Northern Ireland for some time.<sup>13</sup> It is hardly surprising that this trend continued after March 2020, with some of the bereaved people we spoke to acknowledging a lack of clarity around what palliative care should encompass.

Addressing this knowledge gap requires several things – including the provision of accessible and timely information on palliative care. Difficult to get right in the best of circumstances, this has been even harder in the face of the Covid-related service disruptions described above.

### Greater burden on unpaid carers

In cases where the person died at home, people told us that the need to reduce visitors in the house in order to comply with social distancing meant fewer family members or loved ones were able to help provide informal care – resulting in an increased burden on the primary carer.

This also meant a greater responsibility on carers to communicate information about the person’s condition to the wider family network. Carers also faced extra Covid-related delays to practical tasks like processing life insurance policies.

These findings reinforce wider research on the impact of Covid-19 on unpaid carers, which shows a staggering 85% of carers in Northern Ireland providing more care than before the pandemic began.<sup>7</sup> Many end of life carers in Northern Ireland were already struggling to access breaks from caring – facing physical burnout, deterioration in their mental wellbeing and heightened loneliness as a result.<sup>14</sup> For many, this situation has only worsened during the pandemic period.

### Lack of social contact and expedited patient decline

There is growing evidence around the unintended consequences of social distancing – in particular, visiting restrictions in settings like care homes – on the wellbeing of terminally ill people.

For example, in evidence from the Alzheimer’s Society, 79% of care homes reported that the lack of social contact during the pandemic had caused a deterioration in the health and wellbeing of residents with dementia.<sup>15</sup>

Some of the people we spoke to reinforced this trend – arguing that reduced physical contact and lack of stimulation and support as a result of social distancing measures contributed to the decline of their loved ones before they died.

## Advance care planning

**A**dvance care planning (ACP) offers people the opportunity to plan their future care and support.

It ensures they can have realistic and practical discussions about where and how they would like to be cared for at the end of their life, giving them the opportunity to think about what matters to them and to consider and record their wishes and preferences. This may include ceilings of treatment, consideration of things like Advance Decisions to Refuse Treatment and their view on cardiopulmonary resuscitation.

ACP can help to ensure that someone's end of life preferences are respected and realised.<sup>16</sup> It has also been shown to improve satisfaction with end of life care<sup>17</sup> and quality of life,<sup>18</sup> and enhance the chances of someone dying in their preferred place.<sup>19</sup> Knowing that their loved one's end of life wishes were met can also help to improve bereavement outcomes for those left behind.

Advance care planning has perhaps never been more important than in the context of a mass bereavement event like Covid-19, but significant ACP challenges existed before the pandemic and Covid-19 has created further barriers to initiating and recording these conversations.

### Pre-existing barriers

Many people with advanced or life-limiting illnesses in Northern Ireland lack understanding of what advance care planning is, its purpose and benefits. This was evident through some of the people we spoke to, who called for greater

information to aid decision-making on future care planning.

This lack of awareness on the part of patients is sometimes compounded by a lack of confidence in initiating ACP conversations among some health and social care staff groups. Again, this was highlighted by some of the bereaved people in our research, who got the impression that planning for the end of life fell outside of the expertise of some HSC professionals, whose focus was on treatment and curing illnesses.

Elsewhere, practical challenges in recording and sharing ACP decisions across settings have existed for a long time in Northern Ireland. In our conversations, some bereaved people advocated for a primary point of contact for a patient's advance care planning across the HSC system.

More broadly, the people we spoke to described the difficulty of having conversations about dying and end of life plans with their loved ones. Some were unable to countenance these conversations because to do so would mean accepting that their loved one was going to die.

We believe this is an outworking of the wider reluctance to acknowledge or talk about death and bereavement across society. This issue is far from unique to Northern Ireland, but requires much greater policy attention if it is to be addressed locally and underlines the importance of public health approaches to palliative and end of life care (see Appendix). Initiatives in this space have been taken forward by the Department of Health over recent years, but

a much more concentrated approach is needed now.

*“My eyes have been opened to how badly society deals with grieving people.”*

– Bereaved daughter (survey participant)

Finally, some of the people we spoke to gave the impression that ACP conversations were an unwanted encroachment on the limited time their loved one had left.

*“Just because a person is sick, it doesn’t mean every minute of every day has to be taken up with that [thinking and planning about future care].”*

– Bereaved wife (focus group participant)

## New challenges

On top of these pre-existing issues, the pandemic has created several additional barriers.

Sensitive and compassionate consultation with patients and their loved ones about future care options has been more challenging under social distancing measures, shielding and visiting restrictions in care settings like hospitals, care homes and hospices. This may mean ACP opportunities are missed entirely or come at an inappropriate time. It may also result in lack of information-sharing with a patient’s loved ones.

*“[We were] kind of left [with] no clue what was coming.”* – Bereaved daughter (focus group participant)

The additional pressures facing health and social care staff, and reduced access to GPs (key actors in ACP processes), have also reduced the opportunities for ACP conversations.

Finally, the speed at which people with Covid-19 can deteriorate – especially if they are living with other complex comorbidities like dementia or frailty – makes the timeliness of advance care planning conversations even more important.<sup>20</sup>

Limited data is available to assess the impact of these issues, although we may get a partial insight from the PCC shielding survey. Among those survey respondents who were receiving palliative care, over 70% had not discussed advance care planning with a health professional – and of those who had, the majority (68%) had done so prior to the start of shielding.<sup>5</sup>

Interestingly, among those who indicated that they hadn’t had an ACP conversation, a notable proportion (41%) said that they would like to in the future. This suggests that, with the right information and support in place, we could significantly expand the number of people discussing their future wishes and preferences for care.

The Department of Health is currently developing a new ACP policy for Northern Ireland. It is crucial that this is delivered quickly and addresses the new and emerging challenges highlighted in this chapter.

## Experiences and support needs in bereavement

**C**ovid-19 has torn up the rule book on dying, loss and grief. From final goodbyes to funeral rites and bereavement support, the pandemic – and the social distancing restrictions put in place to contain it – has severely disrupted the traditions, customs and sources of support that normally follow a death.

### Growing and complex bereavement needs

As touched on at the beginning of this report, the period of the Covid-19 pandemic has seen an enormous spike in the number of people mourning the death of a loved one. Between the end of March

2020 and March 2021, we estimate that an extra 22,000 people in Northern Ireland were impacted by a bereavement compared to the five-year average.

Not only does that represent a huge increase compared to ordinary years, but the pandemic has fundamentally altered many people's bereavement experiences and, in some cases, created additional complicated grief reactions and needs.

Visiting restrictions in different care settings – while necessary to prevent the spread of Covid-19 – have meant that many people have missed the opportunity to be with their loved ones at the end or say a final goodbye.



This has been shown to impact on measures of complicated grief<sup>21</sup> – a chronic, intense and debilitating form of grief that may last for a long time.

*“There has been a huge amount of guilt for not being with mum when she passed. I’ll never get over that.”*

– Bereaved daughter (survey participant)

*“[It was] very difficult to say our goodbyes on a mobile phone. He was unable to respond. There is 13 [in the family] and his wife held a mobile phone for us all to say our goodbyes. [It was] heart breaking.”*

– Bereaved sister-in-law (survey participant)

Complicated grief can be very damaging for someone’s health and is associated with inflated rates of anxiety and depression,<sup>22</sup> significantly lower Mental Health Index scores<sup>23</sup> and, in some cases, suicidal thinking.<sup>24</sup>

Restrictions around funerals, burials and wakes throughout the pandemic period have also left some people unable to physically attend services to pay their final respects. For others, it has meant lost opportunities to host conventional services or wakes, share stories, celebrate their loved one’s life the way they wanted to or fulfil their final wishes, including important cultural rituals. These issues have also caused enormous distress and severely impacted the grieving process, particularly in the context of regularly changing regulations and restrictions around funerals.

*“The funeral was at my uncle’s home in the garden, but no singing was allowed which really distressed my aunt as my uncle had favourite hymns she wanted to sing. We couldn’t hug or comfort each other, which added an extra layer of loss to the whole funeral experience. [It] just didn’t feel like we got the closure we all needed to grieve properly and move on.”*

– Bereaved niece (survey participant)

*“My mum never wanted a ‘private’ funeral and everyone was to be welcomed... However, as she died right in the middle of Covid, none of her wishes were allowed, which has left me completely devastated... We were only allowed [a] maximum of 10 people at my mum’s grave side service. We were like caged animals locked into the cemetery for 15 minutes and then had to disperse... I couldn’t even have people round to my house for a cup of tea and reflect/share memories of my mum’s life.”*

– Bereaved daughter (survey participant)

It is important to remember that our social networks – including friends and loved ones – play a critical role in providing support when someone dies. The Irish Hospice Foundation’s Adult Bereavement Care Pyramid highlights that the overwhelming majority of people will rely on this support (known as Level 1) after the death of the loved one,<sup>25</sup> but it has been entirely incompatible with social distancing and restrictions on seeing other people in the Covid context.

*“The support around me and our two kids was breath-taking considering the situation, but it doesn’t beat contact and hugs and people being around when you need them.”* – Bereaved wife (survey participant)

We may not yet fully understand the true extent of the bereavement support arising from the pandemic period in Northern Ireland. People told us that the situation described above – along with the ongoing health emergency – has meant their grief is “on pause”, and is something they will only be able to begin processing properly once life returns to some version of normality. Further waves of grief and bereavement support needs, therefore, seem likely to be on the horizon.

### **Barriers to accessing formal bereavement support**

When people have thought about using formal bereavement services during the pandemic period, our research found a number of barriers to accessing it.

There was a lack of understanding and awareness of the type of support available and where to get it among some of the people who shared their experiences with us. They said that this was compounded by the fact that many sign-posting tools – such as information leaflets and posters in public buildings – have been inaccessible. While it is anticipated that this latter challenge will be mitigated when social distancing restrictions are eased, wider problems with awareness of bereavement services may require further attention.

Beyond this, some of the people we spoke to noted that the movement of services from face-to-face to online may be problematic. Many health and social care providers have successfully used digital technology to continue supporting people during the pandemic, but this may not be as effective for bereavement support and counselling, where people may not feel as comfortable talking openly about their experiences with other family members around.

This nuance should be factored into discussions around the increasing digitisation of health and social care services in the post-Covid age.

People identified a number of psychological barriers that they faced to accessing support. Some were reluctant to seek help because they felt they should be able to deal with their loved one’s death without intervention from bereavement services, while others were uncomfortable asking for support.

As above, we would argue that this is another outworking – at least partially – of the reluctance to acknowledge and openly discuss death and dying in Northern Ireland. It may also be linked to social anxieties about appearing “weak” if one needs help, or the stigma attached to the symptoms of mental ill-health that may arise after a bereavement.

Elsewhere, some bereaved described being self-dissuaded from accessing bereavement support because of concerns about the pressure facing these services due to



Phil Hardman/Marie Curie

Covid-19, leading them to feel that they shouldn't add to the burden.

*“There are so many individuals and families suffering because of this pandemic, it seems unfair to try and look for help.”* – Bereaved daughter

(survey participant)

There are parallels here with the reluctance of many people to use GP services or attend A&E in the early months of the pandemic. Some commentators believe this was an unintended consequence of government messages to “protect the health

service”, and it may be the case that this phenomenon had an impact on people's willingness to use bereaved services as well.

Finally, we must remember that capacity pressures existed in statutory and community sector bereavement support in Northern Ireland before Covid-19 came to our shores. This challenge is only likely to have been compounded in the face of a large spike in the number of local bereaved people.

The Covid-19 Bereavement Workstream established by the Department of Health in the early months of the pandemic proposed



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a new Model of Bereavement Care. It builds on the Adult Bereavement Care Pyramid and seeks to ensure that all bereaved people can access the support they need, when and where they need it – spanning community responses through to specialist psychological interventions.

Crucially, it identifies the importance of building capacity in the workforce and delivering training in specialist services to help combat complicated grief. In the context of evidence presented above, it will be important to deliver this new Model of Bereavement Care as soon as possible across Northern Ireland.

At the time of writing, it is envisaged that this will be taken forward by the newly expanded Northern Ireland Bereavement Network, which will also be responsible for delivering the other recommendations of the earlier Department of Health Bereavement Workstream.

### Support in the workplace

Many of the people who shared their experiences with us were working when their loved ones died, and the majority of those we spoke to described positive support from their employers. It was notable, however, that they had to use a combination of special leave, annual leave and, in some cases, sickness absence to get the time off that they needed.

This is concerning, as we do not believe that time off work to grieve the death of a loved one or carry out tasks like funeral arrangements should be treated as a holiday or a type of sickness.

We also uncovered negative experiences, with one person describing the pressure applied by her employer to return to work before she felt ready.

*“My employer at the time was horrendously unsupportive, they did not even send me a card. I was furloughed at the time and when I was unfurloughed (sic) it was 4 weeks after my dad’s death. I told them I did not feel able to return to work and provided a sick line for 2 weeks and they said they were ‘very shocked’ by this and at the end of those two weeks told me ‘it was time I came back to work’ and that ‘it would be good for me’. I found this so offensive given the circumstances of my dad’s death and was made to feel like I wasn’t coping, when it is not unusual to be off for several weeks, if not months, after such a traumatic experience.”*

– Bereaved daughter (survey participant)

The workplace experiences described in this section are very different, but collectively they underline the importance of a minimum entitlement to dedicated and paid bereavement leave in Northern Ireland.

The Department for the Economy has confirmed plans to legislate for statutory parental bereavement leave and pay<sup>26</sup> but we would argue that this policy – while an important step forward – is too narrow in focus. It creates a hierarchy of bereavement by focusing on a single group of bereaved people at the expense of others. Extending this entitlement to all primary caregivers would ensure more people get the time away from work that they need following a bereavement.

# Learning from Covid-19: recommendations for the future

## Ensuring terminally ill people and their loved ones get the care and support they need

- Consideration is needed around improving communication channels between carers/loved ones, terminally ill patients and staff following an admission to care settings like hospitals and care homes.
- Every Health and Social Care Trust should ensure terminally ill patients and their loved ones are aware of, and have access to, a Palliative Care Keyworker (PCK) when they need one, with a universally agreed framework for recording PCK allocation.
- Recurrent funding should be made available to fully implement the Delivering Care programme, in order to deliver the District Nursing workforce needed in NI.
- Support services for unpaid carers should be prioritised in the HSC rebuilding process. The wider social care reform agenda – including the delivery of new legal protections for carers – must be progressed as quickly as possible.

## Expanding access to advance care planning

The Department of Health's new advance care planning policy should be delivered as a priority and cover core areas, including:

- awareness and understanding of advance care planning (ACP) among the public
- confidence and competence in initiating ACP discussions in a timely manner among multidisciplinary health and social care staff
- mechanisms for recording and sharing ACP decisions across care settings.

## Meeting Northern Ireland's growing and complex bereavement needs

- The newly expanded Northern Ireland Bereavement Network should be given all the resources and funding necessary to deliver the recommendations set out by the earlier Covid-19 Bereavement Workstream. In particular, resources/funding should be prioritised for delivery of the Bereavement Care Model and associated measures to boost workforce capacity.
- As part of a wider public health approach to palliative and end of life care (see page 19), measures are needed to raise awareness of bereavement support services and how the public can access them.



- **A conversation is needed around the funding and resourcing of community and voluntary sector bereavement services, with the objective of boosting capacity in these services.**
- **Entitlement to statutory paid bereavement leave should be extended beyond current proposals for parents.**

### **A public health approach to palliative and end of life care**

One overlapping theme that has emerged throughout this report is the reluctance among NI society to discuss and acknowledge death, dying and bereavement. As we have shown, this very often has negative outworkings

for both dying patients and the loved ones left behind.

This challenge is not unique to Northern Ireland, but will only be tackled through a properly resourced public health approach to palliative and end of life care. Efforts have been made in the past, but the Covid-19 pandemic has thrown the importance of this work into sharp focus. The Department of Health, statutory bodies and other key stakeholders should re-double their efforts and scope out a way forward for this project – with a published timetable and accountability mechanisms to monitor delivery. Ideally, this would be delivered under the umbrella of a dedicated outcome on death, dying and bereavement in the NI Executive's Programme for Government.

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## Appendix: A public health approach to palliative and end of life care

**P**ublic Health Palliative Care International defines a public health approach to palliative and end of life care as one that “views the community as an equal partner in the long and complex task of providing quality healthcare at the end of life”.<sup>1</sup>

Six core tenants are at the heart of this approach, including ‘Death Education’ – encompassing public education on issues related to death, dying and loss. This is often pursued through collaboration with institutions including schools, workplaces, churches and more.

Examples that illustrate public health approaches to palliative care in practice include:

- **Cheshire Living Well, Dying Well programme has delivered training to people in public-facing roles to engage their service users in issues of life, age, death and loss. The programme has also delivered bereavement and grief training for students at the University of Chester.**<sup>2</sup>
- **St. Christopher’s Hospice, London has developed programmes to raise awareness of dying and bereavement with local schools. Groups of students aged 9-16 visited the hospice and had the opportunity to talk to staff and patients about terminal illness and bereavement.**

Public health approaches to palliative and end of life care have been found to help expand knowledge and understanding around death, dying and bereavement and address the anxieties that are often attached to them.

Indeed, an evaluation of the St. Christopher’s Hospice programme concluded that it “changed attitudes from uncertainty and anxiety to familiarity and confidence, normalising the experience of death and dying... [and created] healthy relationships between the dying and the broader community”.<sup>3</sup>

These approaches also help to extend the reach of end of life and bereavement services by engaging wider populations beyond those who are dying and their loved ones.

**Further information on public health approaches to palliative and end of life care is available at:**

**Public Health Palliative Care International**  
<https://phpci.info/>

**All Ireland Institute of Hospice and Palliative Care**  
<https://aiihpc.org/wp-content/uploads/2015/02/Briefing-Paper-Public-Health-Approaches-to-Palliative-Care-Nov-2017.pdf>

<sup>1</sup>Public Health Palliative Care International. <https://phpci.info/#!public-health-approach/cee5>

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<sup>3</sup>Kelleher, A (2013). Compassionate communities: End of life care as everyone’s responsibility. QJM, 106 (12)



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