

Bereavement

is everyone's
business





The Right Reverend and Right Honourable Dame Sarah Mullally DBE, the Bishop of London CB

Foreword

All of us will experience grief through the course of our lives. It is a truly universal human experience - part and parcel of being mortal. And as with every aspect of life, we all experience it differently.

Throughout my working life and ministry, I have been alongside people dealing with death and bereavement. As a cancer nurse I would often be with people during those final difficult hours, and in my ministry I have supported people as they struggle to come to terms with someone's death and their own mortality. This has required me to sit with people in those places of deep shadows waiting for light. The light doesn't deny the darkness - but it helps to find some sense of the darkness, giving orientation. My professional background did not take away my own grief when it came and it required me to walk in unknown territory. However, having spoken before about death and bereavement, I had some tools which equipped me on my journey. It is never easy, but all too often I have seen that bereaved people are left with insufficient support at the time when they need it most.

Many of the challenges facing bereaved people have been brought into even sharper relief during the course of the COVID-19 pandemic. Many more people faced bereavement over this period – indeed as this report shows there were an estimated 6.8 million bereavements in the UK over the course of 2020 and 2021 alone, hundreds of thousands more than in prior years.

The pandemic has also had a profound impact on how those affected have experienced bereavement. Many people have been unable to see family and friends and have had limited access to formal support after their loved one died. Feeling alone in their grief due to lockdown or having to shield or self-isolate has had a devastating impact.

At the same time, the pandemic has also spotlighted this universal human experience, presenting an important opportunity to consider how well-equipped we are to support people through a bereavement, and how we can work together to improve that support both now and in the future.

It is in this context that, in June 2021, the UK Commission on Bereavement was founded.

The Commission brought together a coalition of 16 Commissioners, and an advisory group made up of 14 people directly affected by lived experience of bereavement, as well as academics from the Universities of Cardiff, Warwick and Bristol, and a steering group of six voluntary organisations.

Through its work – including taking detailed written and oral evidence from well over a thousand people – the UK Commission on Bereavement has conducted one of the largest ever consultations of bereaved people and professionals working with them.



The Commission has seen time and again that we need to do more as a whole society to support all those affected by bereavement. Ongoing taboos around grief and uncertainties around knowing how to help, however, inhibit support throughout our communities, in our schools, colleges, and workplaces, and even among those whose job puts them in contact with bereaved people every day.

For those who need it, there are significant challenges to accessing formal emotional support. There's not enough of it, it's not accessible to all who need it, and certain groups in society are particularly poorly served.

However, in addition to significant shortcomings in the provision of emotional support, people affected by bereavement often find it hard to get the support that they need with the "practical" challenges they face day-to-day – from registering a death to accessing adequate financial support.

Overall, many people are not getting the right support at the right time, with potentially serious consequences in all areas, from health and wellbeing to education and employment and even long-term economic outcomes.

We must seize the opportunity to change this for the better for people across the four nations of the UK, and not lose sight of the fact that bereavement is an issue for everyone. All our lives will be touched by bereavement at some point, regardless of gender, race, religion, sexuality or age.

It is incumbent upon us all to work together to improve the experiences of bereaved people. This report sets out clear recommendations for how we can achieve this – from ensuring that employers support bereaved staff and schools and education settings provide the opportunity for young people to learn about coping with death and bereavement, through to ensuring that entitlements to financial support following bereavement are extended to everyone who needs them, and improving funding for bereavement services. To deliver all of this, each UK Government must establish and deliver a cross-departmental strategy for bereavement.

By making grief "taboo" – by fearing it and locking it away – we make it all the harder to comprehend, and support each other through it. We make it harder for people to access whatever practical and emotional support, understanding and care they need – be it simply flexibility from one's employer, or help with funeral costs, or access to specialist bereavement support services.

At heart, that's why this Commission is so important: to talk about bereavement; to understand its impact, and the profound challenges that bereaved people can face dealing with both its practical and emotional consequences; to propose the changes that we can make together as a society to improve support for each other through bereavement; and to recognise that grief really is everybody's business.

I pray that this report will go some way to illuminating a path forward and offering new hope for the future.


Acknowledgements

I would like to take this opportunity to thank all those who have contributed in some way to the creation of this report. My fellow Commissioners, whose expertise and insight has proved invaluable in shaping the direction of the *UKCB* and its recommendations. The members of the *Lived Experience Advisory Forum*, who have, with remarkable candidness and bravery, dedicated the time to share their deeply personal experiences of grief with the Commission. Those who responded to the Commission's evidence gathering, be that through our online survey, specialist oral evidence sessions, or through the *Votes for Schools* initiative, bringing the topic of bereavement to 31,000 school and sixth form students. And finally, to all those who have worked tirelessly on the Commission behind the scenes throughout the past year, without whom this report would not have been written.



Key findings of the UKCB report

- 88,070 and 87,780 people were bereaved in Northern Ireland in 2020 and 2021, compared with 78,2340 and 79,610 in 2019 and 2018, with 16,354 excess bereavements
- Over a quarter (28%) of adult respondents to the Commission's consultation received no support from family and almost half (46%) received no support from friends following bereavement
- 61% of adult respondents had difficulties with at least one practical or administrative task following bereavement
- 44% of respondents who wanted to access formal emotional support said no support was available. 38% said they didn't know how to access support



“Family zero, friends zero, community zero. Pretty much left to it with disabled children to manage.”

MAN, 41-50, WHOSE WIFE DIED





Eight principles for change

1

I am supported by my family, my friends and the communities around me

2

I am sensitively supported by my school, college or workplace during my bereavement

3

I am well supported during the death, and feel confident that the person who died received appropriate and compassionate care

4

The things I must do after a death are simple and straightforward

5

I am compassionately and helpfully supported by those whose job brings them into contact with me through all stages of my bereavement

6

I have access to an affordable and meaningful funeral

7

I feel secure in my home and have the right financial support

8

I can easily find and access the right emotional bereavement support for my circumstance



Key recommendations

- **Ministers in Northern Ireland should commit to developing a new, cross-departmental bereavement strategy that recognises support following bereavement as a human right**
- **All education establishments should be required to have a bereavement policy, and provide opportunities for children and young people to learn about coping with death and bereavement as part of life**
- **Statutory bereavement leave and pay entitlement of 2 weeks should be reviewed with a view to extension**
- **All public, private and third sector bodies supporting bereaved people should commit to tackling inequalities in access to bereavement services and support and ensuring underserved communities, including ethnic minorities, marginalized groups and other groups whose grief is disenfranchised, are better supported**

Bereavement in Northern Ireland; the current landscape

Bereavement is a universal experience. It will touch all our lives at some point and when it does it will impact on each of us differently. The COVID-19 pandemic has not only exacerbated challenges around bereavement, it has also spotlighted it, presenting a rare opportunity to consider how well equipped we are to support people through a bereavement, and how we can work together to improve that support both now and in the future. It has been widely recognised as a global health pandemic – but it could equally be described as a mass bereavement event.

Northern Ireland has not been immune to this trend. Between the end of March 2020, when the first lockdown restrictions were introduced, and March 2021, nearly 18,500 deaths were recorded here – a 15% rise on the five-year average. In addition to that nearly 90,000 people in Northern Ireland were impacted by a bereavement in 2020 alone, with thousands more bereaved than in previous years as a result of the pandemic.

Deaths from COVID-19 also brought an increasing trend of inequality to those bereaved, with mortality rates in the most deprived areas exceeding those in the least deprived areas during the pandemic months. It is also important to note that grief experienced by bereaved people in Northern Ireland was significantly compounded by the severe disruption from COVID-19 to the traditional family, religious and community death rituals that are deeply embedded in our culture.

In addition, the extent and complexity of grief in Northern Ireland should also be considered in the context of our history of recurrent tragic deaths and how as a society, we are still emerging from years of conflict, with a legacy of over 3,500 'Troubles' related deaths. In response to the profound impact this consolidated grief has had across our society, NI's Department of Health commissioned a dedicated task group in 2020, the COVID-19 Bereavement Workstream, to develop practical guidance on the development of services and resources to address the bereavement needs of people impacted by the pandemic.

The Workstream made 8 key recommendations including the establishment of the Northern Ireland Bereavement Network, with responsibility for developing and leading Northern Ireland's strategic bereavement plan for the next 10 years. The Bereavement Network would also consist of representatives from the statutory, voluntary & community sectors and be responsible for progressing the remaining recommendations made by the task force.



The NI Bereavement Network was subsequently established in March 2021 with a cross sectoral membership of dedicated bereavement experts across NI and importantly included the voice of people with lived experience of bereavement, as an essential element in shaping this work. Led by the DoH, the Network is supported by four sub-groups currently progressing bereavement initiatives in the following areas:

- **Development of a new informative NI Bereavement Website aimed at supporting the NI public,**
- **Development of comprehensive Education and Learning resource to support bereavement service providers,**
- **A co-production approach to designing and developing a dedicated NI Bereavement Charter,**
- **Plans to design a new NI Bereavement Strategy, with consideration of an overarching framework strategy to encompass existing and planned living (Advance Care Planning), dying (Palliative and End of Life Care) and grieving (Bereavement) strategies.**

The NI Bereavement Network's work will continue into the medium to long term as it delivers on its strategic remit and commitment to support people in NI who have been so devastatingly impacted by loss before, during and beyond the COVID-19 pandemic.

The Network was also pleased to be involved in the UK Bereavement Commission's work on the bereavement landscape across the four nations and in drafting its recommendations ([view all reports here](#)). This short report aims to summarise that collaborative activity, to highlight the common human experience across UK nations and our united vision to improve the bereavement experience for all our citizens.



The UK Commission on Bereavement

The independent UK Commission on Bereavement was established in June 2021 to investigate this topic through research and consultation. It is chaired by The Right Reverend and Right Honourable Dame Sarah Mullally DBE, the Bishop of London, who is joined by 14 Commissioners reflecting diverse professional and cultural backgrounds from across the four UK nations including **Professor Nichola Rooney, Chair of the British Psychological Society Division of Clinical Psychology NI**. The Commission has been supported by a steering group made up of voluntary organisations working in partnership with academics and guided by people with personal experience of bereavement through its Lived Experience Advisory Forum (LEAF).

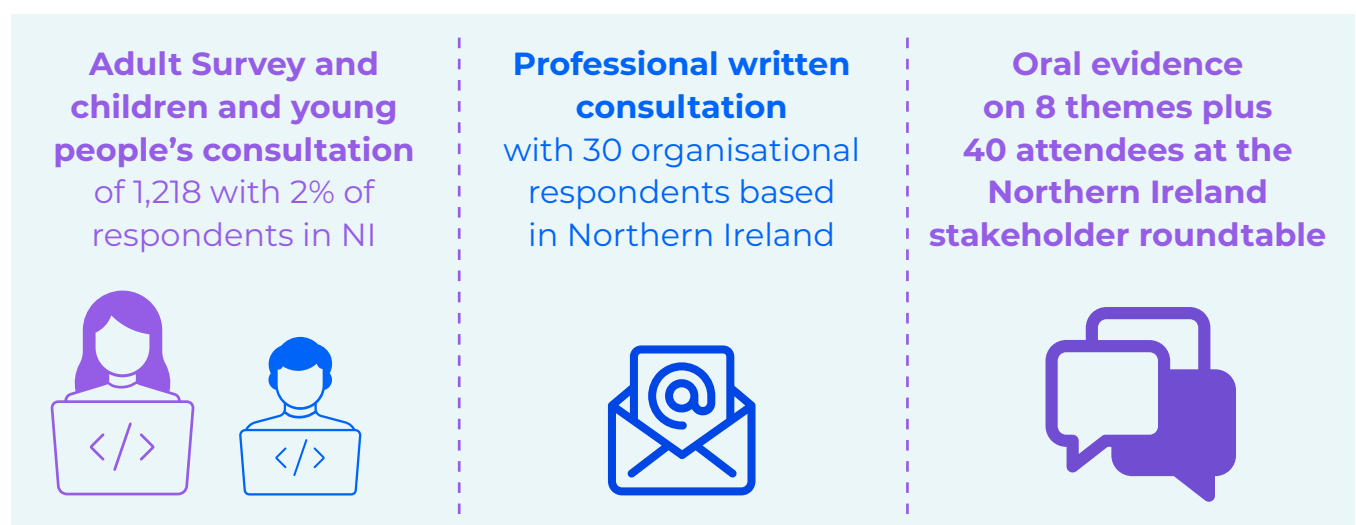
The Call for Evidence

Between Autumn 2021 and March 2022, the UK Commission on Bereavement heard from more than a thousand bereaved individuals, as well as organisations and professionals working with bereaved people, on experiences of bereavement and the support needs of people who have been bereaved before, during and beyond the COVID-19 pandemic.¹

“After the funeral [my employer] kept asking when am I coming back? So felt I had to go back probably at a time I wasn’t ready. Was supposed to be phased return but wasn’t. When I returned a few thought I had been on holiday that was quite hard to hear.”

WOMAN IN HER 40S WHOSE FATHER DIED OF CANCER (NORTHERN IRELAND)

The Commissioners heard oral evidence from 33 experts on eight different topics and stakeholder roundtables were held in all four nations of the UK, with almost 40 members of the NI Bereavement Network and UK Bereavement Commission attending in Northern Ireland, as well as wider NI stakeholders. The Northern Ireland roundtable event was chaired by the NI Commissioner for the UK Bereavement Commission and included updates from both NI DoH on the work of the NI Bereavement Network and the UK Bereavement Commission.



¹ 2% of written responses to the adult and children and young people’s written consultations were from respondents based in Northern Ireland, which is proportional to the UK population’s distribution with 2.8% in Northern Ireland

Organisations which attended

- NI Social Care Council
- Commissioner for Older People NI
- Belfast HSCT
- Public Health Agency
- Alzheimer's Society
- South Eastern HSCT
- Western HSCT
- Southern HSCT
- Cruse Bereavement Support
- Samaritans
- SANDS
- Lighthouse
- NI Ambulance Service
- Horn of Africa People's Aid Northern Ireland NI Hospice
- Northern HSCT
- Department of Health
- Barnardo's
- NI Ambulance Service
- Patient and Client Council
- Ulster University

Roundtable Core Themes which fed into the Commission's evidence

- 1 Public attitudes and engagement – exploring how employers, schools, faith groups and other community organisations/societal sectors can better support people who have been bereaved.
- 2 Practical support in bereavement – how support could be better provided with administration of practical tasks after bereavement, and the financial support needs of people who have been bereaved.
- 3 The impact of the COVID-19 pandemic – including the unique and/or unequal impact of the pandemic on different groups of people who have faced bereavement, and innovations in practice which could provide lessons for the future.



Our vision for change

Recommendations

Based on the rich and extensive evidence submitted to the Commission we have identified eight key principles for improving bereavement experiences in Northern Ireland, with corresponding recommendations for achieving each of these.

To deliver all these recommendations, Ministers in Northern Ireland should establish and deliver a cross-departmental strategy for bereavement, in partnership with bereaved people, that recognises support following bereavement as a human right. This should:

- **encompass all aspects of public policy affecting bereaved people**
- **draw on learning from the pandemic to set out how people (public, communities and workforce) will be supported in future mass bereavement events.**
- **set out the responsibilities of central and local government, health and social care commissioners and other statutory bodies, and**
- **address inadequacies in support for ethnic minorities, marginalised groups, and others who are particularly poorly served**

1. I am supported by my family, my friends and the communities around me.

Friends, families, neighbours, and faith communities all have the power to provide excellent - and for many people sufficient - support, through a bereavement. But it is crucial that these groups are equipped to support people effectively.

- 1 All schools & other education settings, should be required to provide age-appropriate opportunities for children and young people to learn about coping with death and bereavement.

2. I am sensitively supported by my school, college or workplace during my bereavement.

Education settings and workplaces are key communities for bereaved people as the places where many spend most of their time. Good support in these contexts is vital to enable people to stay and to thrive in education and employment and we must ensure nobody misses out.

- 1 Department for the Economy should publish guidance on minimum standards and best practice for large, medium sized and small employers on bereavement policies including paid leave, with specific guidance on support for those who experience death and bereavement in the course of their work, written in consultation with all relevant stakeholders in the public, private and third sectors.
- 2 Statutory bereavement leave and pay entitlement of 2 weeks should be reviewed with view to extension
- 3 Department of Education should require that all education establishments (early years, schools and further and higher education) have a bereavement policy including staff training, and a process for supporting a bereaved child or young person and their family



3. I am well supported before and during the death, and feel confident that the person who died received appropriate and compassionate care

Experiences around the time of death have a profound impact on how bereaved people experience their grief. More needs to be done to ensure that as many people as possible experience a 'good death' and that there is greater continuity of information and support to people through a bereavement.

- 1 To ensure an integrated approach to delivery of care before, during and after a person's death, Ministers in Northern Ireland should ensure that palliative and end of life care strategies are effectively linked to bereavement support strategies.

4. The things I must do after a death are simple and straightforward

At an already difficult time, many newly bereaved people are faced with a large volume of practical tasks and paperwork, which are often complex, duplicative, and difficult – practically and emotionally.

- 1 UK Government should legislate so that people can choose whether to register a death in person or online, and NI councils should implement this
- 2 Ministers in Northern Ireland should conduct a review of the flow of information from death registration to relevant public bodies and industry, including the feasibility of introducing a service for streamlining the notification of a death, similar to 'Tell Us Once' in GB
- 3 Northern Ireland Departments and regulators should make sure bereaved customers are treated fairly and sensitively by working with relevant industry groups to develop minimum standards for death administration processes.

5. I am compassionately and helpfully supported by those whose job brings them into contact with me through my bereavement

Through a bereavement, there are numerous points of interaction people need to have with different organisations and businesses, from registering the death, to sorting out financial affairs, through to organising the funeral.

- 1 Professional bodies and employers of those whose role brings them into contact with bereaved people must ensure they have bereavement training that is culturally-informed and contextually tailored, including training on complex and traumatic grief, at an appropriate level.

6. I have access to an affordable and meaningful funeral

Funerals and other forms of memorialisation can be very helpful in people's experiences of grief, but too many people currently miss out, or are forced to compromise, on these. More needs to be done to ensure all bereaved people have access to a meaningful funeral:

- 1 The Competition and Markets Authority must carry out its proposed further market enquiry into the funeral industry now the exceptional circumstances of the pandemic are passed
- 2 The UK Government must create new regulations setting out minimum standards for public health funerals
- 3 Funeral Expenses Payment should be extended to currently excluded groups including students



7. I feel secure in my home and have the right financial support

In addition to the emotional and practical challenges following a bereavement, many bereaved people face financial difficulties too, and some are forced out of their home. The evidence gathered by the Commission has exposed some of the inadequacies in the current financial support available to those who need it, with some groups being systematically excluded. This must change in the following ways:

- 1 Entitlements to financial support following a bereavement should be reviewed with a view to extending to key groups including:
 - » Bereavement Support Payment extended to cohabiting partners and those whose partner was unable to make sufficient National Insurance contributions due to sickness or disability
 - » Funeral Expenses Payment extended to students
 - » Ministers in Northern Ireland should work to increase uptake of Pension credit
- 2 Financial support following a bereavement should be extended beyond current time limits:
 - » Benefits for carers extended to 6 months after death (up from 2 months)
 - » Bereavement Support Payment extended to 6 years / completion of 1 year of secondary education for the youngest child (up from 18 months)
 - » Exemption from bedroom tax extended to a year (up from 3 months)
- 3 All benefits for bereaved people should be up-rated annually in line with inflation in all four nations
- 4 With a view to future legislation Department for Communities should publish best practice, recommending that landlords give at least 6 months' notice for an eviction when an original tenant dies. This must apply to all tenancies in both the private and social rented sectors.

8. I can easily find and access the right emotional bereavement support for my circumstances

While good support from friends and relatives is sufficient for most people who are bereaved, some people will need more formal emotional support. The evidence has highlighted a range of issues with the current support available, with some groups being particularly poorly served. More must be done to ensure support is available, accessible to and appropriate for all who need it:

- 1 Bereavement services and support (including that provided by communities and faith groups) should sign up to an agreed set of standards, including ensuring they meet the diverse needs of the communities they serve.
- 2 NICE should develop guidelines for the delivery of bereavement support at all levels, including for complex and traumatic grief, such as facilitating access to appropriate mental health services when necessary.
- 3 All public, private and third sector bodies supporting bereaved people should commit to tackling inequalities in access to bereavement services and support and ensuring underserved communities, including black and other racially minoritised communities and other groups whose grief is disenfranchised, are better supported.
- 4 Ministers in Northern Ireland should commission further research to better understand the support needs of people affected by bereavement with a particular focus on understanding how services can be improved for black and other racially minoritised communities and other groups whose grief is disenfranchised. The voice of people affected by bereavement must be central to this research.



Find out more about the UK Commission on Bereavement

For more information about the UK Commission on Bereavement, the full research report, summary report and full recommendations please go to www.bereavementcommission.org.uk

To get in touch about the Commission please contact ukcb@mariecurie.org.uk



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