

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.



New findings on experiences of bereavement from Commission

Key findings of the Commission's report:

- In 2020 and 2021, 130,000 people died in Scotland, causing an estimated 649,000 bereavements. This was an additional 64,000 bereavements compared to what would have been expected based on the five-year average from 2015-2019
- 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
- Over 40% of adult respondents who wanted formal bereavement support did not receive any



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

MAN, 41-50, WHOSE WIFE DIED





Our vision for change

Evidence submitted to the Commission identified many different challenges associated with bereavement, as well as examples of good practice. Based on this evidence, eight key principles have been identified for improving bereavement experiences, with corresponding recommendations.

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 for Scotland:

- 1 Scottish Government must commit to developing a new, cross-departmental bereavement strategy that recognises support following bereavement as a human right
- 2 Scottish Government must invest 79p per person in the population for transforming bereavement services over the next five years, with particular focus on better supporting Black, Asian and ethnic minority communities, those experiencing financial hardship and others who are poorly served
- 3 All Scottish education establishments must have a bereavement policy, and provide opportunities for children and young people to learn about coping with death and bereavement as part of life
- 4 All Scottish employers must work towards the National Bereavement Charter
- 5 The National Care Service must commission tailored bereavement support and signposting

The full list of recommendations for Scotland is available [here](#).

Bereavement in Scotland: the current picture

Bereavement is a universal experience, which will touch us all, and impact each of us differently. It is estimated that 328,000 people were bereaved in Scotland in 2021, compared with 290,000 in 2019, pre-pandemic. The pandemic has not only exacerbated existing challenges around bereavement and complicated grief, it has spotlighted a crucial opportunity to consider how well services are equipped to support people through a bereavement, and what needs to happen to improve that support both now and in the future.

The National Bereavement Charter was published in Scotland in 2020, with principles which describe what bereavement support and care should look like. The Commission recommendations will build on this in Scotland, in addition to the extensive work and resources of [NHS Education Scotland \(NES\) Bereavement](#).

The UK Commission on Bereavement

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The Commission has been supported by a steering group made up of the voluntary organisations: Marie Curie, Independent Age, Cruse Bereavement Support, the National Bereavement Alliance, the Childhood Bereavement Network and the Centre for Mental Health, working in partnership with academics from Cardiff University, the University of Bristol and the University of Warwick.

The Commission's work has also been guided by people with personal experience of bereavement through its Lived Experience Advisory Forum (LEAF).



Key findings of the Commission and implications for Scotland

The Commission's work and principles have explored, and been informed by, the experiences of bereavement both during the pandemic (2020-2022) and more widely.

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

Bereavement can be an exceptionally isolating and lonely experience. Where available, support from family, friends and communities can play a critical role in providing comfort and connection through grief. Adults, children and young people highlighted the importance and value of the practical and emotional support they received from friends, relatives, neighbours and faith communities following their bereavement. Many said they could not have coped without it, but many also described this support as lacking or problematic.

Evidence from the Commission highlighted where some existing informal networks of support that are available in some communities, such as death and grief cafes, bereavement walks, and compassionate communities are working well. However, there are still significant challenges around:

- **Stigma around certain types of deaths**
- **Poor understanding of how adults, children and young people grieve, including the longevity of grief**
- **Family responsibilities including protecting others and managing changed family dynamics and strained relationships.**

During the pandemic, these experiences were exacerbated as infection control measures meant that many people had to remain “physically separate” from family, friends and communities following a bereavement, and as a result also felt “emotionally separated”, 74% of bereaved adults experienced social isolation and loneliness

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

MAN, 41-50, WHOSE WIFE DIED

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

Schools, colleges and workplaces are settings where people can spend a large proportion of their time, and therefore, must be fully equipped to provide ongoing support through the emotional and practical challenges of a bereavement. There are some examples of best practice, including access to informal or formal bereavement support. However, inadequate support in these settings risks contributing to poor outcomes in all areas of a person's life, from mental health to potentially long-term employment and economic prospects:

- **A third of adult respondents felt “not at all” or “only a little” bit supported by their employer**
- **Just under half of children and young people felt ‘not at all’ or ‘only a little’ supported by their school or college, especially young people aged 13–18**



- **Barriers to good support across all these settings included:**

- » Lack of awareness and understanding of grief and how to support students and employees
- » Poor communication and information sharing
- » Inflexible systems.

I suffered PTSD and a breakdown and had to change my job to part time as I couldn't cope.

WOMAN IN HER 50S WHOSE HUSBAND DIED OF A BLOOD CLOT

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

The circumstances in which a person dies and the care and support they, and those close to them, receive has a profound impact on long-term experiences of grief. The Commission identified aspects of a good end-of-life experience which included:

- **Culturally sensitive anticipatory care planning**
- **Frequent and effective communication with staff**
- **Continuity of care pre- and post-bereavement.**

However, the care and support people and their loved ones receive at the time of their death varies enormously and many key challenges of end-of-life care were identified:

- **Respondents thought that the care and support received from professionals around the time of death varied hugely, with perceived inequalities across different settings**
- **People whose relative died suddenly, in a hospital or a care home, or was from an ethnic or religious minority background consistently identified shortfalls in the care that they received around the death**
- **The pandemic profoundly disrupted experiences around death. Among respondents bereaved during the pandemic:**
 - » 65% reported limited contact with their loved ones before their death
 - » 54% said they were unable to say goodbye as they wanted
 - » 42% said they had issues with a lack of support from professionals.

“Unable to share what was going on in my head with family or friends, they surely must of been suffering also”

MAN IN HIS 50S WHOSE WIFE DIED FROM CANCER

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

Bereaved people face many practical and administrative responsibilities and tasks after a bereavement, which are often both complex and time sensitive. These include death registration, notifying a wide range of organisations (from banks and energy suppliers and the council to social media sites) as well as legal and coronial processes.

Tell Us Once, a Department for Work and Pensions (DWP) service, enables a recently bereaved person to report a death to most government organisations in one instance. This and other initiatives working to simplify administrative processes have helped to reduce some of the administrative burden felt by bereaved people.



However, the Commission found many challenges still causing distress:

- **61% of adult respondents with administrative responsibilities reported difficulties with at least one practical or administrative task**
- **39% of respondents had difficulty sorting out financial affairs**
- **21% of adults had difficulties registering a death.**

Respondents also reported difficulties at all stages of death administration including;

- **Not knowing what to do**
- **Not being aware of the wishes of the person who died**
- **Feeling overwhelmed by both the volume and complexity of tasks**
- **Facing inefficiencies and delays from organisations.**

“All so confusing and when you are so exhausted it’s all a struggle.”

MAN IN HIS 50S WHOSE WIFE DIED OF A TERMINAL ILLNESS

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

When navigating difficult administrative tasks associated with a death, the sensitivity and skill of public facing staff is crucial, and we know is valued by people experiencing bereavement.

However, there is still huge variability in bereaved people’s experiences of organisations, with many examples of poor communication and treatment. Bereaved people reported a range of communication problems with staff across the full range of administrative processes after a bereavement, including:

- **Coldness and lack of empathy**
- **Insensitive comments and behaviour**
- **Ignorance and insensitivity to minoritised religious and cultural requirements.**

These were exacerbated by restrictions to in-person services during the pandemic and the shift to remote working.

I have access to an affordable and meaningful funeral

Being able to acknowledge a person’s death and celebrate their life are important aspects of healthy grieving. The Commission found having a funeral, and other forms of memorialisation to be extremely important to people’s wellbeing and experiences of grief, to provide a safe space and opportunity to express emotions and share grief with others.

However, funerals can add to the already high administrative burden on bereaved people, and the financial pressures people face after a bereavement. While some bereaved people have the practical and financial resources to enable a fitting funeral, and access to culturally appropriate ceremonies, many still do not. The Commission found this creates additional distress and can impact profoundly on experiences of grief:

- **one in five (22%) of all adults responsible for death administration reported difficulties arranging the funeral**



- **over three-quarters (76%) of respondents bereaved during the Covid-19 pandemic said that restrictions placed on funerals made grieving and coping with their bereavement(s) more difficult.**
- **people accessing public health funerals (funerals arranged and paid for by local authorities because no one else is able to do so) experienced stigma, lack of information and sometimes official discouragement from using this service.**

“Going by the most recent data, the average funeral expenses payment covers, the award only covers 41% of the average cost of a simple funeral, and the funeral support payment in Scotland on average covers only 50%. And the main problem of those payments is the capped portion of the payment...a thousand pounds is very, very rarely enough, so it can leave the bereaved with a significant shortfall that they are unable to pay.”

ORGANISATION'S ORAL EVIDENCE

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

Bereavement can often be a trigger into financial insecurity and poverty, with many people experiencing bereavement at particular risk of financial hardship. This is particularly the case for bereaved partners or spouses, where the bereavement commonly results in the loss of household income (for example, loss of wages, benefits and pension-based income) and may sometimes even result in a bereaved person or family losing their home.

The Commission found these financial pressures significantly add to emotional stress and grief:

- **more than 4 in 10 said a bereavement had resulted in financial difficulties for themselves or their family**
- **navigating financial support and the benefits system to access the ‘right’ entitlements is complex and difficult to manage**
- **some financial support is currently only available for bereaved spouses and excludes unmarried partners (including those with children) as well as the partners/spouses of people who have not paid enough National Insurance**
- **the current amount and duration of the financial support on offer is inadequate for many people, especially those with children**
- **kinship carers are denied statutory support despite often facing significant practical and financial challenges when they take on responsibility for a bereaved child/children following the death of their parent(s)/guardian(s)**

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

Some people will also need formal emotional support to help with their bereavement. The Commission found that those who received formal emotional or psychological support generally found it helped, providing a safe non-judgmental space to discuss their grief, and an opportunity to learn coping strategies to help them move forward in life and in their grief. However, many are still faced with significant difficulties getting the right support, including:

- **stigma associated with seeking professional help**
- **lack of proactive signposting to emotional support to cope with a bereavement**
- **lack of support appropriate to individual needs (including age, ethnicity, religion and type of death).**



Long-standing issues with lack of service coordination and inadequate funding to deliver tailored bereavement services is still extremely prevalent in Scotland. Organisations identified a wide range of underlying challenges affecting their capacity to deliver services that are responsive to the needs of the people they serve, including:

- **lack of statutory funding for bereavement services**
- **lack of appropriate training for supporting specific group needs (for example, ethnic minorities, people with learning disabilities)**
- **not enough collaboration and coordination between voluntary and statutory services, at a local or national level.**

What needs to happen next?

There is a crucial opportunity which must be taken by decision makers to improve bereavement support for those affected by dying, death and bereavement in Scotland, and we are calling for the following urgent action.

Key recommendations for Scotland:

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For further information please contact:

Ellie Wagstaff

Policy and Public Affairs Manager, Marie Curie

E: Ellie.Wagstaff@mariecurie.org.uk

Claire Donaghy

Head of Scotland, Independent Age

E: Claire.Donaghy@independentage.org

