

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 the UK Commission on Bereavement

Across the UK, more than 1.3 million people died in during 2020 and 2021, resulting in an estimated 6.8 million bereavements (ONS). The COVID-19 pandemic has not only exacerbated challenges around bereavement, it 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.

Working in partnership with a number of UK third sector organisations and university researchers, in June 2021 an independent UK Commission on Bereavement was established to investigate this topic through research and consultation across all four nations of the UK. The Commission's work has also been guided by people with personal experience of bereavement through its Lived Experience Advisory Forum (LEAF).



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Family zero, friends zero,
community zero.
Pretty much left to it with
disabled children to manage.
MAN, 41-50, WHOSE WIFE DIED

The Bereavement Commission's call for evidence

The Commission received 1,119 responses to its survey of adults affected by bereavement, as well as many additional responses from children and young people. It also heard from 130 organisations, and through the organisation Votes for Schools, from 31,000 students on issues of grief education.

The Commissioners also heard oral evidence on eight different topics as well as from a series of stakeholder roundtables in Scotland, Wales, Northern Ireland and England, and from key mental health sector representatives and faith leaders from many different religions.

Key findings

- **There were 6.8 million bereavements in the UK in 2020 and 2021, with 750,000 additional 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.**

Throughout its work, the Commission heard that we need to do more as a whole society to support all those affected by bereavement, but ongoing taboos around grief, and uncertainties around knowing how to help, 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.

Changing this will require concerted action throughout society, but there must be strong leadership from those with the most power to enact change – national governments across the UK.



Recommendations

The rich and extensive evidence submitted to the Commission identified many different challenges associated with bereavement, as well as examples of good practice and suggestions for improvement. Based on this evidence we have identified eight key principles or 'I' statements which we want everybody to be able to say, with corresponding recommendations for achieving each of these.

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. That is why we are making the following recommendations:

- 1 In order to increase understanding and normalise conversations about death, dying and bereavement, governments in each UK nation must commit 6p per person to help develop, resource and evaluate cross-sector, collaborative initiatives similar to public health campaigns reducing mental health stigma such as Time to Change and See Me. These must reflect the needs of all communities in the UK, and prioritise underserved population groups. This funding should supplement funding for the transformation of bereavement services set out in the recommendation below and have a particular focus on community-based informal support, and communication campaigns

These initiatives will be led by networks of charities, academics, community-based organisations, faith groups, compassionate communities and health and social care providers, co-produced with people with lived experience

- 2 All schools and other education settings must be required to provide age-appropriate opportunities for children and young people to learn about coping with death and bereavement as part of life.

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. While some schools, colleges and workplaces already support bereaved people well, we must ensure nobody misses out, by making following changes:

- 1 New legislation must require that all employers have a bereavement policy. Relevant government departments should publish guidance on minimum standards and best practice for large, medium-sized and small employers. These should include specific guidance on support for those who experience death and bereavement in the course of their work, and should be written in consultation with all relevant stakeholders in the public, private and third sectors
- 2 Statutory bereavement leave and pay entitlement of 2 weeks must be extended to encompass all close relationships
- 3 All education establishments (early years, schools and further and higher education) must be required to 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, with concerted action from all Governments across the UK:

- 1 Professional bodies and employers of anyone 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
- 2 Each UK Government must ensure that there is sustainable funding and effective delivery of palliative care services
- 3 To ensure an integrated approach to delivery of care before, during and after a death, all UK Governments must 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. We are calling for the following changes to ease this burden on grieving people:

- 1 Governments across the UK must legislate so that people can choose whether to register a death in person or online
- 2 Governments across the UK must conduct a review of the flow of information from death registration to relevant public bodies and industry, including the feasibility of extending the remit of Tell Us Once
- 3 Government departments and regulators must ensure 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. The following change must be made to ensure bereaved people are treated fairly and feel supported at every step:

- 1 Professional bodies and employers of anyone 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 investigation into the funeral industry now the exceptional circumstances of the pandemic are passed
- 2 New regulations must be created setting out minimum standards for public health funerals
- 3 Funeral Expenses Payment must be extended to currently excluded groups including students
- 4 Out of hours systems must be in place in every local authority to enable rapid processing of death paperwork and registrations so that quick burials can take place for people whose religion requires it (for example Jewish and Muslim communities).

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 must be extended to key groups including:
 - » Bereavement Support Payment extended to cohabiting partners and those whose partner was unable to make sufficient NI contributions due to sickness or disability
 - » Ensuring that those with No Recourse to Public Funds (which prohibits access to most mainstream benefits as a result of someone's immigration status) are not denied the financial support they need following a bereavement. This includes extension of the Funeral Expenses Payment to this group.
 - » Funeral Expenses Payment extended to students
 - » Governments across the four UK nations must work to increase uptake of Pension Credit
- 2 Financial support following a bereavement must 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 must be up-rated annually in line with inflation in all four nations
- 4 Legislation must require 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 and accessible to and appropriate for all who need it. We are therefore making the following recommendations:

- 1 Bereavement services and support (including that provided by communities and faith groups) must sign up to an agreed set of standards, including ensuring they meet the diverse needs of the communities they serve.
- 2 NICE and SIGN must 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 In order that everyone has access to good and appropriate bereavement support, governments in each UK nation must invest 79p annually per person in the population for transforming bereavement services over the next 5 years, with a particular focus on better supporting Black, Asian and ethnic minority communities, and others who are currently poorly served. As well as service delivery, it must cover:
 - » Quality improvement including training and tailoring of support
 - » improvements in assessment, signposting and referral mechanisms to mental health services for people affected by complex grief
 - » Local and national collaboration
 - » Research, data collection and evaluation
 - » Innovation in practice, including trialling new approaches to signposting support, and piloting the feasibility and effectiveness of offering bereavement support proactively to specific underserved and vulnerable groups.
- 4 All public, private and third sector bodies supporting bereaved people must commit to tackling inequalities in access to emotional support following a bereavement and ensuring underserved communities, including Black, Asian and ethnic minority communities and groups whose grief is disenfranchised, are better supported.
- 5 All UK Governments must commission further research to better understand the emotional support needs of people affected by bereavement with a particular focus on understanding how services can be improved for Black, Asian and ethnic minority communities and groups whose grief is disenfranchised. The voice of people affected by bereavement must be central to this research.

To deliver all of the above recommendations, each UK Government must establish and deliver a cross-departmental strategy for bereavement that recognises support following bereavement as a human right. This must:

- **Encompass all aspects of public policy affecting bereaved people**
- **Involve the voices of 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 national and local government, health and care commissioners and other statutory bodies, and**
- **Address inadequacies in support for Black, Asian and ethnic minority communities, and others who are particularly poorly served.**

Next steps

Over the last year, the UK Commission on Bereavement has heard from more than a thousand people affected by bereavement and organisations and professionals who work with them, to better understand the impacts of bereavement, and the changes needed to improve support both now and in the future.

However, identifying the changes needed is just the start. If we are to make a reality of the vision set out in this report, Governments, organisations across the public, private and third sectors, and all of us in communities across the UK, must work together to deliver ongoing change in policy, practice, and culture.

The Commissioners, and the organisations who have supported the Commission's inquiry, very much look forward to working with all those willing to help to transform support for bereaved people, and in doing so, improve everybody's experience of bereavement across the UK.





Eight principles for change

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

2 I am 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



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 bereavementcommission.org

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

