

# Bereavement is everyone's business





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

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### 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

Bereavement is a universal experience. It will touch all of our lives at some point and when it does it will impact on each of us differently.

In 2020 and 2021, 74,000 people died in Wales, causing an estimated 368,000 bereavements. This was an additional 34,000 bereavements compared to what would have been expected based on the five-year average from 2015-2019. 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 voluntary organisations and University researchers, **including Dr Emily Harrop from Cardiff University**, in June 2021 an independent UK Commission on Bereavement was established to investigate this topic through research and consultation in all four nations of the UK. The Commission is chaired by The Right Reverend and Right Honourable Dame Sarah Mullally DBE, the Bishop of London, who is joined by 15 Commissioners, including **Dr Idris Baker, Chair of the National Bereavement Steering Group**, and previously **Lesley Bethel, who was Chair of Compassionate Cymru** [www.compassionate.cymru](http://www.compassionate.cymru). The Commission's work has also been guided by people with personal experience of bereavement through its Lived Experience Advisory Forum (LEAF).

*“My family didn't understand and my friends - even though amazing- I felt so isolated. I was so desperate to be around mums who had experienced what I did.”*

WOMAN IN HER 40S WHOSE DAUGHTER WAS STILLBORN AND WHOSE SISTER-IN-LAW AND TWO GRANDPARENTS ALSO DIED (WALES)

# Bereavement Policy Context

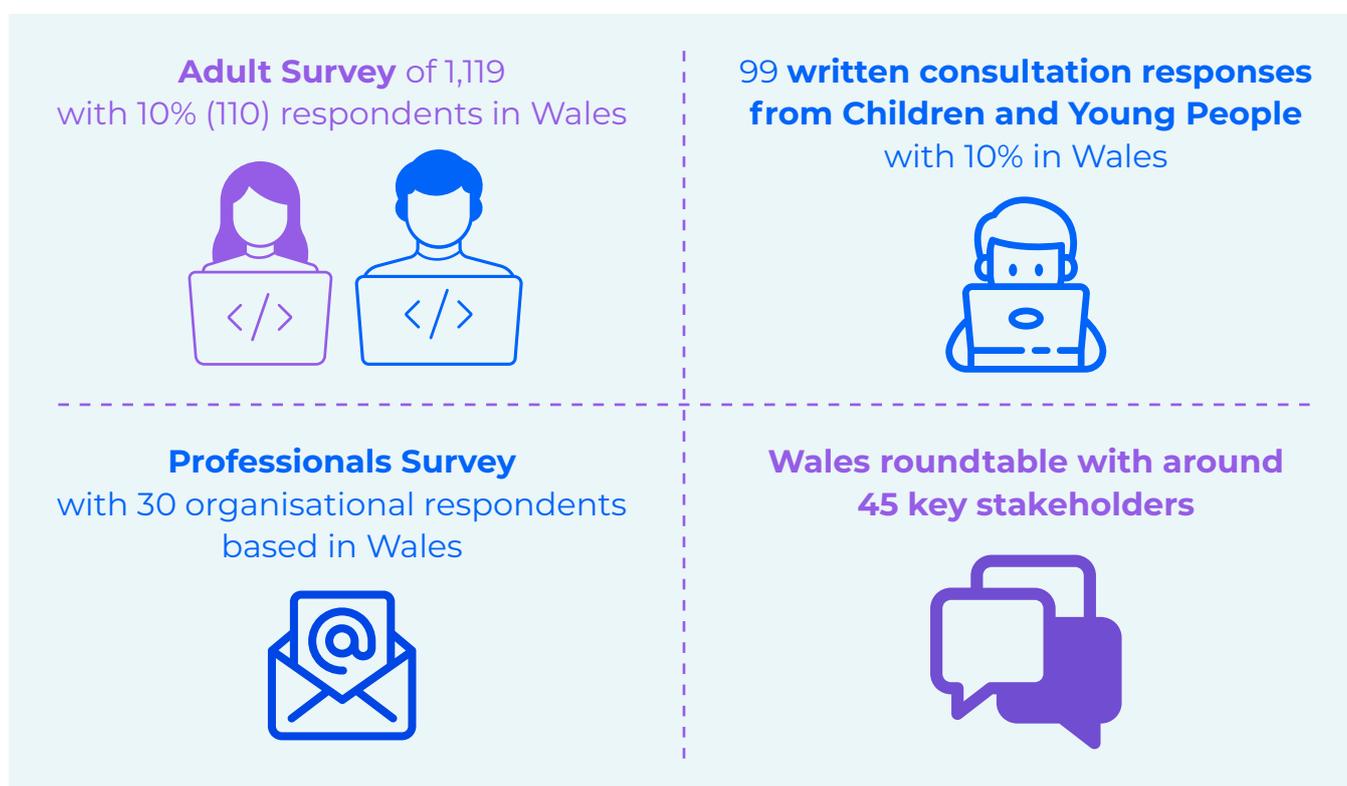
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Significant progress has been made in Wales over the last few years with regard to improving bereavement support. In October 2021, the National Framework for the Delivery of Bereavement Care in Wales was launched. The National Bereavement Steering Group is currently working to implement the Bereavement Framework in Wales, which includes the development of an overarching “pathway” for bereavement in Wales, as well as more specific pathways for different types of bereavement.

A £1 million bereavement support grant has been provided alongside the framework for each year, from 2022-2024. An extra £420,000 has also been made available to health boards in 2022-2023 and 2023-2024, to help with coordination and implementation of the new standards.

## The Bereavement Commission’s call for evidence

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The Commissioners heard oral evidence on eight different topics as well as from a series of stakeholder roundtables, including one in Wales with around 45 attendees, ranging from health and social care professionals, bereavement support workers, funeral directors, third sector colleagues and individuals attending in a personal capacity. The event was attended by the Deputy Minister for Mental Health and Wellbeing.

# Key findings

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- 187,000 people were estimated to have been bereaved in Wales in 2020, compared with 166,000 in 2019, pre-pandemic
- Over a quarter (28%) of UK 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 UK 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.

**“I was isolated. I had little to no support. I was alone and in deep pain. My family turned inward and took care of each other whilst my physical separation from them meant I was separated emotionally too. Nobody took care of me”**

WOMAN AGED 18-30 WHOSE GRANDFATHER DIED OF CANCER (WALES)

Findings from the evidence in Wales were consistent with those across all other nations of the UK.

## Key Recommendations:

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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 in Wales.





# Eight principles for change

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

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

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

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

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

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**6** I have access to an affordable and meaningful funeral

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

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



Corresponding recommendations to support decisionmakers across Wales to achieve each of these principles are given in the section below. Due to reserved Westminster powers, some recommendations listed below are to be driven by the UK Government. However, Welsh Government and other key stakeholders in Wales have a duty to support and promote these changes to benefit the Welsh population.

## Key Recommendations for Wales:

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- 1 Welsh Government must implement their National Framework for the Delivery of Bereavement Care using a cross-departmental approach. 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
  - » draw on 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.
- 2 In order that everyone has access to good and appropriate bereavement support, Welsh Government 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 poorly served. As well as service delivery, it must cover:**
  - » quality improvement including training and tailoring of support
  - » improvements to access to mental health services for people affected by complex grief
  - » local and national collaboration
  - » research, data collection and evaluation
  - » innovation in practice, including new approaches to signposting support and piloting the feasibility and effectiveness of and offering bereavement support proactively to specific underserved and vulnerable groups.
- 3 All public, private and third sector bodies supporting bereaved people must commit to tackling inequalities in access to bereavement services and support and ensuring underserved communities, including Black, Asian and ethnic minority communities and other groups whose grief is disenfranchised, are better supported**
- 4 Welsh Government must 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, Asian and ethnic minority communities and other groups whose grief is disenfranchised. The voice of people affected by bereavement must be central to this research.**



## 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, Welsh Government must commit 6p per person to help develop, resource and evaluate cross-sector, collaborative initiatives. These must reflect the needs of all communities in Wales, prioritising under-served population groups. This should supplement funding for the transformation of bereavement support services set out above, and have a particular focus on community-based informal support, and communication campaigns. Compassionate Cymru must play a role in this work alongside Welsh Government.
- 2 These initiatives will be led by networks of charities, academics, community-based organisations, faith groups, compassionate communities and health and social care providers, and co-produced with people with lived experience.
- 3 All schools and other education settings in Wales, 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.

## I feel well supported before and during the death and feel confident that my relative received appropriate and compassionate care

- 1 Welsh Government must ensure that there is sustainable funding and effective delivery of palliative care services.
- 2 To ensure an integrated approach to delivery of care before, during and after the death of someone, Welsh Government must ensure that palliative and end-of-life care strategies are effectively linked to bereavement support strategies.

## The professionals I am in contact with at all stages through my bereavement are compassionate and helpful

- 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.

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

- 1 UK Government must legislate so that people can choose whether to register a death in person or online, and this must be implemented by Welsh local authorities
- 2 The Competition and Markets Authority must carry out its proposed Funeral Market Investigation into the funeral industry now the exceptional circumstances of the pandemic are passed
- 3 UK Government must create new regulations setting out minimum standards for public health funerals, which must be implemented by Welsh local authorities



## I have access to an affordable and meaningful funeral

- 1 Out of hours systems must be in place in every local authority in Wales 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).
- 2 All education establishments (early years, schools and further and higher education) in Wales 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.

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

- 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.

## I can easily find and access the right emotional bereavement support that recognises my needs and circumstances

- 1 NICE 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.

# 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](http://bereavementcommission.org)

To get in touch about the Commission please contact [ukcb@mariecurie.org.uk](mailto:ukcb@mariecurie.org.uk)

