

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; 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.



Bereavement in the UK

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.

Across England and Wales alone, 1.2 million people died during 2020 and 2021, with a further 130,000 in Scotland and 35,000 in Northern Ireland. This left an estimated 6.8 million bereavements. This is an additional 750,000 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 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.

Working in partnership with a number of 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.

UKCB Key Findings

- **6.8 million people were bereaved in the UK in 2020 and 2021 compared to 6.1 million in 2018 and 19, with 750,000 additional bereavements¹**
- **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**
- **33% of respondents who wanted to access bereavement services but indicated no support was available and 37% said they didn't know how to access support**
- **Over 40% of those who wanted formal bereavement support did not get any**

1. Compared to what would have been expected based on the five-year average from 2015-2019



The UK Commission on Bereavement

The Commission is chaired by The Right Reverend and Right Honourable Dame Sarah Mullally DBE, the Bishop of London. She is joined by 15 Commissioners reflecting diverse professional and cultural backgrounds from across the four UK nations (appendix 1).

The Commission has been supported by a steering group made up of a number of third sector organisations: Marie Curie, Independent Age, Cruse Bereavement Support, National Bereavement Alliance, Childhood Bereavement Network and Centre for Mental Health, working in partnership with academic researchers: Dr Emily Harrop at Marie Curie Palliative Research Centre at Cardiff University, Dr Lucy Selman at the University of Bristol and Dr Catherine Grimley at the University of Warwick.

The Commission's work has also been guided by people with personal experience of bereavement. A Lived Experience Advisory Forum (LEAF) was set up at the beginning of the commission, made up of fourteen individuals bereaved in the last five years, who met regularly throughout the course of the Commission's work to review progress and advise on its direction.



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. Evidence was received by the commission both orally and in writing.

Written evidence:

- **Online survey responses from 1,119 adults bereaved in the last 5 years, conducted between September 2021 and January 2022**
- **Written consultations with 99 bereaved children and young people, conducted between November 2021 and February 2022**
- **Online survey responses from 130 organisations and professionals working with bereaved people, conducted between September 2021 and January 2022**
- **Engagement with 31,000 school and college students in classrooms through the organisation Votes for Schools in January 2022.**

Oral evidence:

The Commissioners heard oral evidence from 33 experts on eight different topics. Witnesses spoke predominantly from organisational perspectives and experiences of working with people affected by bereavement, although some people also shared personal stories.

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Session Topics:

**Public attitudes
to bereavement**

**Financial impact
of bereavement**

**Children and young people's
experiences of bereavement**

**Those underserved
in the sector**

End-of-life experiences

**Funeral industry
and death administration**

**Older people's experiences
of bereavement**

**Groups whose grief
is disenfranchised**

Stakeholder roundtables were held in all four nations of the UK, with two further sessions involving key representatives from the mental health and bereavement sectors, and leaders of different faiths and community groups.



Findings and recommendations

The impact of bereavement:

“A very lonely place to be”

“It is quite hard at times it’s really like a roller coaster, you could be feeling good one minute then you have a big moment where all of your emotions come out.

13-15 YEAR OLD”

Facing a bereavement can be one of the most profound upheavals any one of us experiences. The evidence submitted to the Commission indicated that the impacts of grief are both intense and wide ranging, touching all areas of life. The emotional impacts of grief vary and are changeable over time, often lasting for many months or years in different forms. While most people are able to continue with their existing responsibilities after some time, for some people intense emotional pain does not go away. Grief has physiological impacts, practical impacts on work, school and home life and also people’s longer term economic wellbeing.

The pandemic has had a profound impact on how those bereaved during this time have experienced death and grief. Many people have experienced unexpected and sudden deaths, been unable to see family and friends and have had limited access to formal support after the person they were close to died.

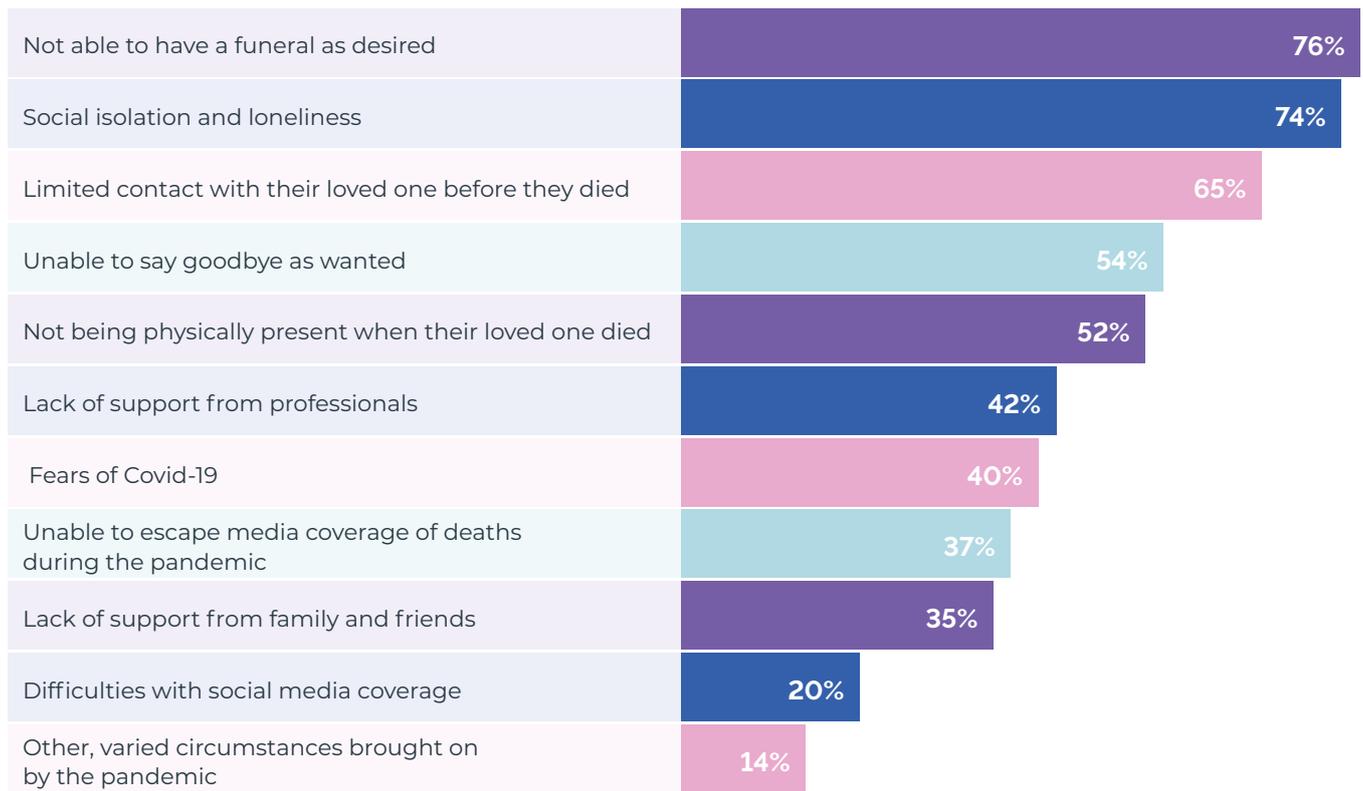
These feelings of being alone in their grief due to lockdown, and having to shield or self-isolate, have been devastating. The lack of face-to-face contact from primary care and community-based support services, and bereavement support services, has also been more difficult.

Complexity of bereaved people’s presentation has increased. We are seeing more trauma. More prolonged grief, more complex grief reactions.

ORGANISATIONAL RESPONDENT



Prevalence of difficulties related to the pandemic among adult bereaved during the Covid-19 pandemic (n=757)



The graph above demonstrates different ways in which so many people were impacted by pandemic restrictions, as well as societal responses to it. Whilst several of these experiences were clearly specific to the pandemic, a number of these difficulties (although exacerbated by COVID-19) were more enduring, demonstrating the need for a long-term vision and agenda for change.

“Losing my husband devastated me and I suppose all of my past sadness enveloped me. I didn't want to carry on.”
WOMAN AGED 51-60 WHOSE HUSBAND DIED OF CANCER”



Our vision for change

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.

That is why we have set out our vision for all bereaved people as a series of 'I' statements. These are the things we want all bereaved people across the UK – our friends, family, neighbours, ourselves - to be able to say. We know there is still a long way to go. To help us get there, and to convince decision makers to take action, we have used the evidence and suggestions people shared with us to set out a series of recommendations.





8 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 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 circumstances



1

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

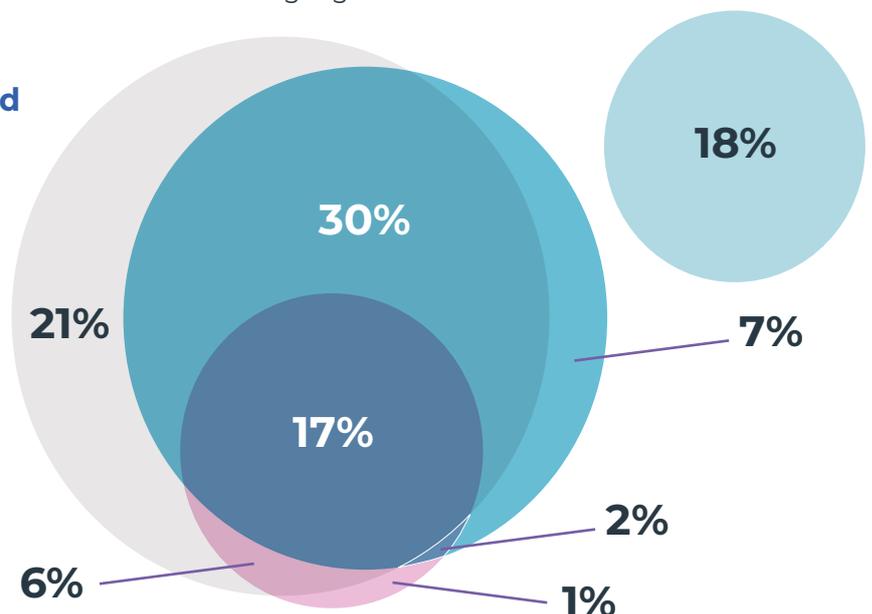
“ I was isolated. I had little to no support. I was alone and in deep pain. My family turned inward and took care of each other whilst my physical separation from them meant I was separated emotionally too. Nobody took care of me.
A WOMAN (18-30 YEARS OLD) WHOSE GRANDAD DIED OF CANCER. ”

“ Immediately my sad news spread round the village help and support was there. I went out daily round the village just to meet people who knew me and/or my daughter and we cried and laughed together as she was such a well-loved person by everyone who knew her.
WOMAN IN HER 70S, WHOSE DAUGHTER DIED OF SEPSIS ”

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.

The evidence highlighted informal networks of support that are available in some communities, such as death and grief cafes, bereavement walks, and compassionate community initiatives. Organisations described how these projects help to normalise the conversation around death, dying and bereavement as well as bring people together to share their experiences and have an opportunity to talk. However, regional disparities in the availability of such networks were highlighted.

Types of informal support used (n=1,119)



Key challenges with informal support:

- Over a quarter (28%) of adults received no support from family
- Almost half (46%) received no support from friends
- Nearly one in five (18%) received no support from any informal source (family, friends, faith communities or co-workers).

Barriers to support from friends, family and communities included:

- Ongoing taboos around dying, death and bereavement
- Stigma around certain types of deaths
- Poor understanding of how adults, children and young people grieve, including the longevity of grief
- Limited awareness of how to support someone and what to say
- Not wanting to be a burden on others
- Family responsibilities – 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 felt “emotionally separated” too.

Your family try to act like everything's okay and don't like bringing it up because it makes everyone upset.

**YOUNG PERSON
AGED 13 -15**

Friends checked up on me, however it felt (and still feels) like they have their own busy lives and I don't want to burden them with my sadness.

**A WOMAN WHOSE HUSBAND
DIED OF COVID-19**

As a society, we are still overwhelmingly uncomfortable talking about death, dying and bereavement, and in supporting people who are grieving. We are calling for the following changes to help to normalise conversations and improve support among all communities.

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 a later recommendation 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, 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

Schools, colleges, universities, and workplaces where people spend a large proportion of their time, and should feel they 'belong', are an incredibly important part of the community around a bereaved person.

As well as providing important social networks and stability, these settings are also places where people have to work or study. They are well placed to provide ongoing support through the emotional and practical challenges of a bereavement. Examples that were given of good support in these settings included providing:

- **A compassionate culture**
- **Time off when needed and other reasonable adjustments**
- **Access to informal or formal bereavement support through bereavement charities, employee assistance programmes, or peer networks.**

Inadequate support in these settings increases the risk of poor outcomes in all areas of a person's life, including mental health, long-term employment and economic prospects. The evidence highlighted a number of challenges experienced by bereaved people at work or in education.

When I rang my boss to tell him my daughter was in the hospice and I was taking the rest of my annual holiday, he asked me how long I would be away for, I had to point out I didn't know how long it would take her to die. I only got five days paid leave, at the end of that time we hadn't even got a date for the funeral. When I did get back to work, my colleagues had all been told not to talk about my daughter's death 'in case it upset me' so nobody mentioned my darling girl: I felt like a ghost drifting aimlessly around the office with no one noticing me.

WOMAN IN HER 50S WHOSE DAUGHTER DIED OF CANCER

My granddaughter's school was brilliant and continues to be supportive of her and her dad, they got the local child bereavement charity to come and talk to all the staff when my daughter died. As a family we had been working with them and this ensured that the school and the family were all using the same language to my then 5-year-old granddaughter.

WOMAN IN HER 50S WHOSE DAUGHTER DIED OF CANCER

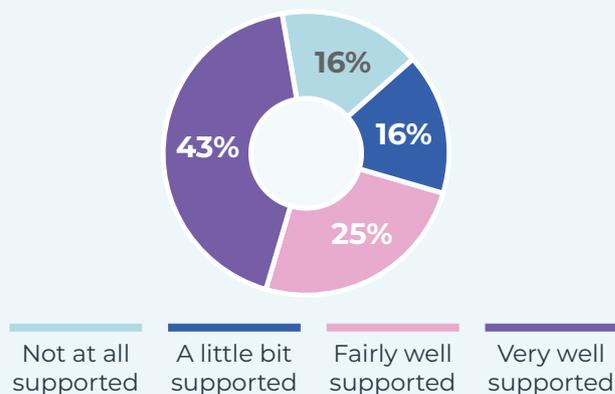


Key challenges with work and education settings:

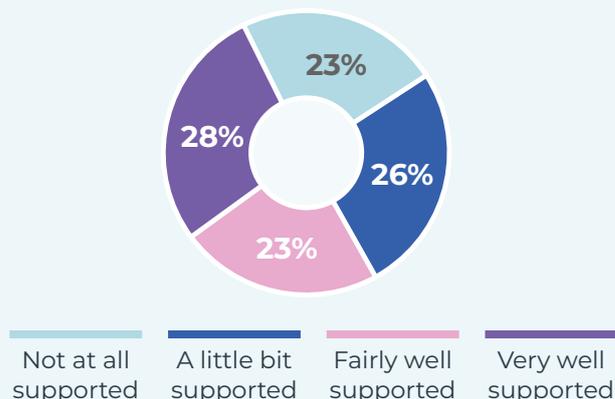
- **A third of adult respondents felt not at all or only a little bit supported by their employer, and a half felt supported by their educational setting**
- **Just under half of children and young people we heard from (n=32/65) felt not at all or only a little supported by their school or college. This was especially the case amongst those aged 13-18.**
- **In workplaces, there was variation in all aspects of support including:**
 - » Supportive cultures
 - » Paid leave
 - » Returning to work
 - » Long term flexibility and adjustments
 - » Access to employee assistance programmes
 - » Access to workplace bereavement networks
- **In education settings variation in support included:**
 - » Communication and information sharing
 - » Adjustments and sensitivity to the bereavement over time
 - » Access to bereavement support
- **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.

The evidence shows that there is still a long way to go to ensure bereaved people are adequately supported in these important contexts. We are calling for the following changes in employment and education policy and practices.

Ratings of support from employers (n=697)



Ratings of support from education settings (adults n=133)



Recommendations:

- 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



B

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

“ I had to demand the necessary medications. Poor Mum had no glasses or hearing aids- all lost in hospital which made communication impossible. My bereavement experience was awful remembering only the trauma I saw.

**WOMAN IN HER 60S
WHOSE MOTHER DIED OF COVID-19**

“ We were able to speak to [the family] on a daily basis and reassure her and reassure them, and we worked out a plan and a programme to enable us to make changes in the home to enable her to come out. When she passed, everybody, including people on video from America and her priest, was able to say goodbye to her on the last day. And when she held our hands and squeezed — so, it's not all negative. But that's what we've got to look for: the best, and the best is good care, especially at that time.

ORAL EVIDENCE

The circumstances in which a person dies and the care and support they, and those close to them, receive around the time of death has a profound impact on long-term experiences of grief. Good aspects of end-of-life care that were identified included:

- **Culturally sensitive advance planning**
- **High quality and holistic end-of-life care**
- **Frequent and effective communication with staff**
- **Continuity of care pre- and post-bereavement**
- **Access to early and appropriate emotional and bereavement support.**

However, the care and support people and their loved ones receive at the time of their death varies enormously and many problematic features of end-of-life care were identified in the evidence.



Key challenges in end-of-life care and support:

- Respondents thought that the care and support received from professionals around the time of death varied hugely, citing inequalities across different settings, groups, and types of death
- People whose relative died suddenly, died in a hospital or a care home, or was from an ethnic or religious minority background consistently identified shortfall in the care that they received around the death
- The pandemic profoundly disrupted experiences around death. Among respondents bereaved during the pandemic:
 - » 65% reported difficulties with limited contact with their loved ones before they died
 - » 54% said they were unable to say goodbye as they wanted
 - » 42% said they had issues with a lack of support from professionals
 - » 52% said they were not physically present when their loved one died
- It also exposed and exacerbated the following existing, underlying issues:
 - » Variation between different settings and types of death
 - » Strained and inadequate health care systems
 - » Systematic insensitivity to minority religious and cultural needs.

There is a need to improve support for people who are dying and those close to them across all settings and causes of death, especially when death takes place suddenly, in hospitals or care homes, and among racially and culturally minoritised communities. Reflecting this imperative for properly funded, holistic palliative and end-of-life care, greater continuity of care, and compassionate, appropriately skilled workforces, we are calling for the following changes to health and social care.

“
Improve end of life care in Hospitals.
I saw it is still not holistic, as a palliative care nurse I knew the excellent standards of a Hospice, not seen in the Hospital.
”
**WOMAN WHOSE MOTHER
DIED OF COVID-19**

Recommendations:

- 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

“
When you are newly bereaved, you are expected to organise a huge array of practical things- at a time when you feel exhausted, confused and at a loss. It adds to the pressure and anxiety you feel. What can be done legally and practically to ease this burden for grieving people?

**WOMAN IN HER 50S
WHOSE AUNT, MOTHER-IN-LAW
AND FATHER IN LAW DIED**”

“

18 months later, I still haven't sorted out financial affairs - life insurance, TPS pension ... there are forms to fill in that I just can't get my head around. It's like a foreign language to me. And I'm trying to navigate it on my own.

Very stressed about it.

**WOMAN IN HER 50S WHOSE
HUSBAND DIED OF COVID-19**”

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

Tell Us Once is a cross-government service, which enables a recently bereaved person to report a death to most government organisations in one instance. This and other initiatives to simplify administrative processes have helped to reduce some of the burden felt by bereaved people. However, many challenges prevail, causing stress and distress to people already grappling with the emotional turmoil of recent bereavement.

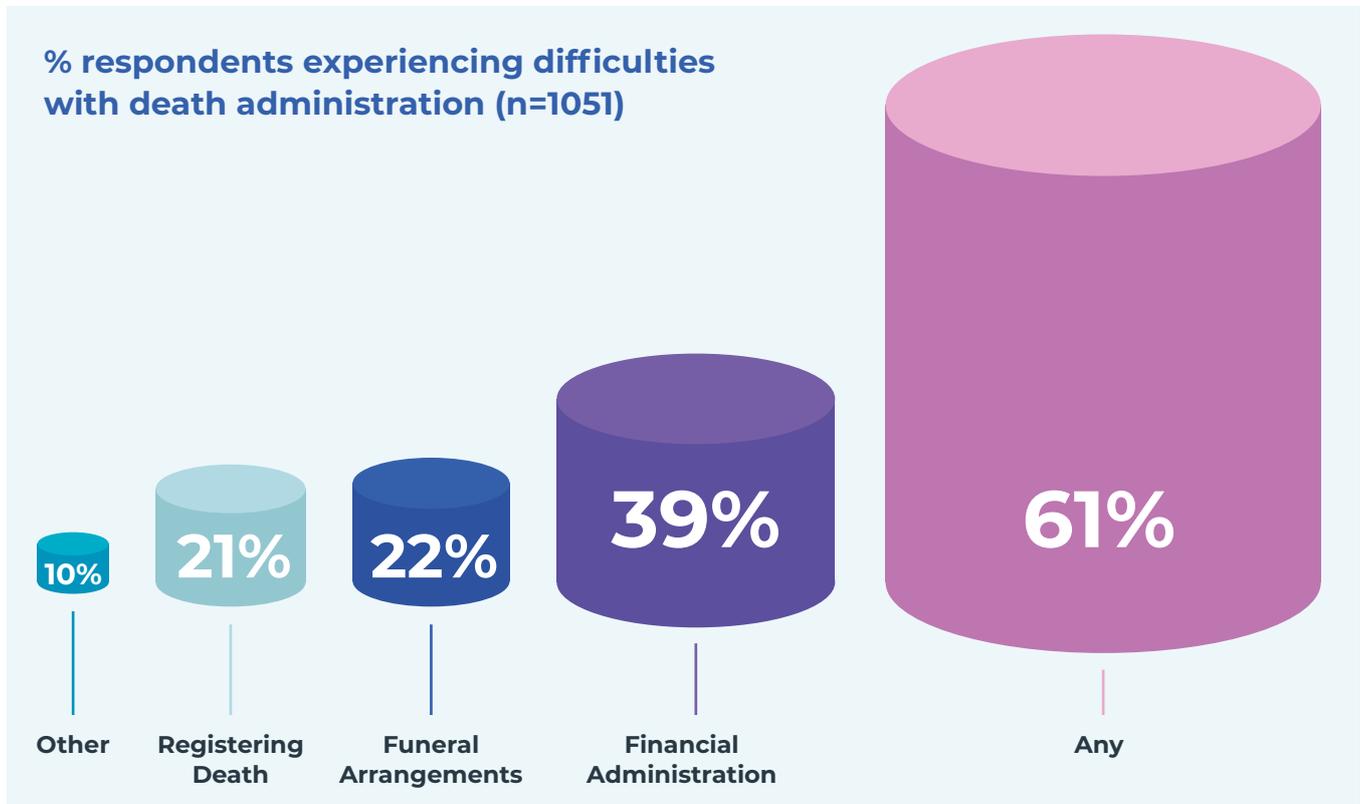
Key challenges with death administration:

- **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**
- **10% had difficulties with other practical responsibilities (for example, coroners, utility accounts, vacating/selling houses)**



- **Respondents 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
- » Feeling under time pressure to complete tasks
- » Facing inefficiencies and delays from organisations



The complexity and volume of administrative tasks stem from a lack of streamlining and coordination across death administration processes. While the Tell Us Once service goes some way to addressing the volume of Government paperwork, more needs to be done to ease the burden on grieving people. We are calling for the following changes to death administration processes.

“ Having to make the calls and explain that your husband is dead. I cried on the phone every single time.

WOMAN WHOSE HUSBAND DIED OF CANCER ”

Recommendations:

- 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

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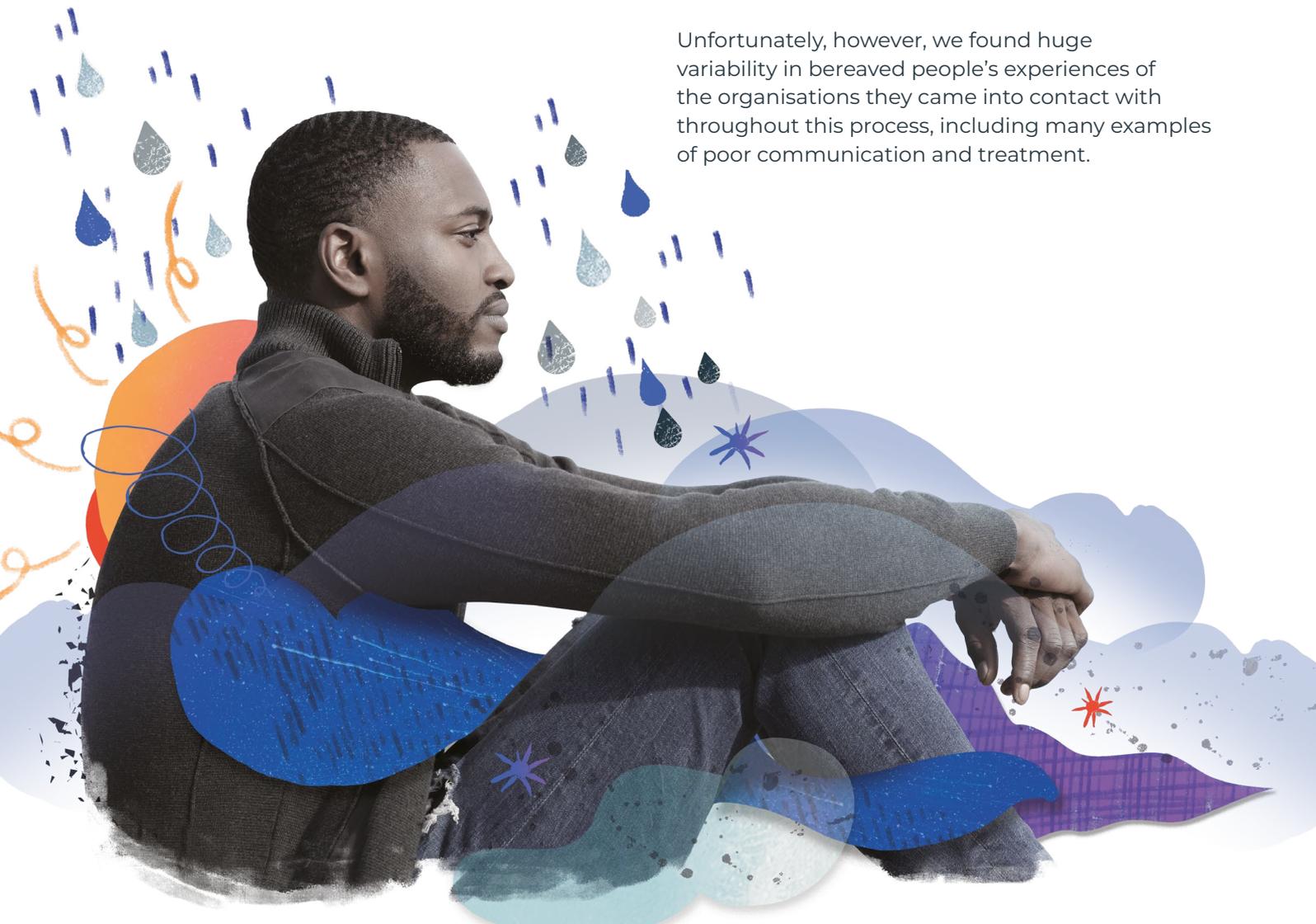
Not knowing what to do next, do I call the police, the GP? The funeral director was my rock to guide me through the whole process.

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

”

As highlighted in the previous section, bereaved people face many challenges around death administration relating to not knowing what to do, and the high number of organisations they need to contact after the death. When navigating these difficult tasks, the sensitivity and skill of public facing staff is crucial. In addition to practical guidance and advice, respondents valued instances of sensitive and compassionate treatment by some of the professionals that they encountered, including funeral directors and staff at banks and energy companies.

Unfortunately, however, we found huge variability in bereaved people's experiences of the organisations they came into contact with throughout this process, including 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**
- **Lack of knowledge of the processes that need to take place when someone dies**
- **Ignorance and insensitivity to minoritised religious and cultural requirements**
- **These were exacerbated by restrictions on in-person services during the pandemic and the shift to remote working.**

“Organisations not being set up to respond to and be kind to grieving families. My mother found this particularly upsetting. Lots of telephone queues, being told for example at the bank she couldn't speak to someone in private.

**WOMAN WHOSE FATHER
DIED OF SEPSIS**”

“I often struggled to find the right person in a company to talk to and they obviously had not had training to deal with the bereaved. Often, [my partner] was referred to as my ex, I was offered an upsell in terms of financial products, sometimes the person at the other end of the phone became emotional after hearing my baby in the background. Many companies or organisations had a robot to sort callers and ask for a reason to call but my reason for calling did not fit in with what it was able to understand.

**WOMAN AGED 18-30 WHOSE PARTNER
DIED OF CARDIAC ARREST**”

It is vital that bereaved people are better supported through the administrative process following the death of someone close to them.

They need to be treated compassionately, not just around the death but throughout their bereavement. The workforce also needs to be skilled to support people affected by more complex and traumatic bereavement, as well as bereavement in exceptional circumstances (such as a pandemic). This is why we are making the following recommendations for relevant employers and professional bodies.

Recommendations:

- 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

Being able to acknowledge a close person's death and celebrate their life appropriately and meaningfully are important aspects of 'good' or healthy grieving. Respondents found having a funeral, and other forms of memorialisation to be extremely important for their wellbeing and their experiences of grief. Funerals and other forms of memorialisation provide a safe space and opportunity for bereaved people to express their emotions and share their grief with others.

However, funerals can add to the already high administrative burden on bereaved people, and the financial pressures they 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 others do not. This creates additional distress and can impact profoundly on experiences of grief.

There is a need for guidance around organising a funeral: more diverse and culturally sensitive funeral directors and suppliers; financial support for those who need it including better public health funerals; and regulation of the funeral industry. It is also crucial that people are better supported in future pandemics, and that wellbeing considerations relating to funerals are carefully balanced with the need to control the spread of infection. We are making the following recommendations for the funeral sector.

Key challenges with funerals and memorialisation

- **One in five (22%) of all adults responsible for death administration reported difficulties arranging the funeral. These included;**
 - » knowing what to do,
 - » being able to pay for the occasion
 - » accessing a religiously and culturally appropriate ceremony (especially amongst minoritized communities)
- **Over three quarters of respondents bereaved during the Covid-19 pandemic (76%) reported disruption to funeral arrangements. These included;**
 - » Not being able to attend a funeral at all
 - » Holding services which were very different from what they or their loved one would have desired.
- **People experience problems accessing public health funerals (funerals arranged and paid for by Local Authorities because no one else is able to do so)**
 - » These include stigma, lack of information and sometimes official discouragement of people using this service.

“Now, there is a saying in the Caribbean, “I need to pay my respects” and that word respects, is not just used lightly, it is very important to Caribbean people, it is very, very important. What has happened through COVID, we have lost the opportunity to pay our respects and for that, a lot of us have not had proper closure

ORAL EVIDENCE



Recommendations:

- 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 The 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)

“ Yes, it was sudden and unexpected. None of us had any savings at all for the funeral or to buy funeral clothes.

WOMAN IN HER 40S WHOSE SON DIED IN AN ACCIDENT”

I did a poem at the funeral and it made me feel proud I did it.

CHILD AGED 5-12



7

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

“ The Bereavement Support Allowance is currently not available to unmarried couples. We have two children that I need to raise singlehandedly now and with the loss of a second income that has stretched us with everything that we, especially the children, will need normally now and over the next 5 to 10+ years.

MAN IN HIS 30S WHOSE PARTNER DIED OF COVID 19

“

The banks were unsympathetic and unyielding. They froze the accounts that the mortgage and all direct debits were paid from. This meant his final salary payment couldn't be paid in. Then, having been told by the so-called bereavement team that I would get a couple of months grace on the mortgage while the death in service was processed, they started sending scary mortgage default letters after the first payment was missed (which was because the account was frozen and so I hadn't been able to access his salary payment).

WOMAN IN HER 40S WHOSE HUSBAND DIED OF CANCER

”

Bereavement can often trigger financial insecurity and poverty with many people experiencing bereavement at particular risk of financial hardship and changes to their material circumstances and living conditions. This is especially 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. Such pressures add significantly to the emotional stress and grief of the individual or family, including children and young people.

Key challenges with financial support and welfare:

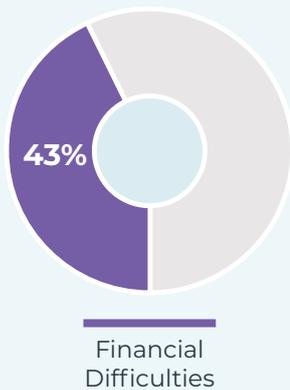
- **More than 4 in 10 respondents to a question on financial difficulties (43%), told the commission that bereavement had resulted in financial difficulties for themselves or their family**
- **Navigating the financial support and benefits system to access the 'right' entitlements is complex and difficult 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**

CONT. >>



- **The current amount and duration of 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)**
- **Financial hardship and some tenancy agreements mean that surviving family members can find themselves having to move house, or in some cases facing homelessness, soon after the death.**

Financial difficulties caused by bereavement (n=697)



“Bereavement Support Payment assumed the lone parent would be able to function normally in 18 months’ time, which could not be reasonable as different people cope differently.
WOMAN WHOSE HUSBAND DIED OF A HEART CONDITION”

Adequate financial support, a social security/welfare system that is easier to navigate, and greater protection for those at risk of eviction is needed to mitigate the financial hardship suffered by so many bereaved people across the UK. We are recommending the following changes to tenancy law and the social security and welfare system.

Recommendations:

- 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

“ My counsellor also allowed me time to explore my grief and all of the stresses and new responsibilities within my life. They were a constant presence when everything else was all in turmoil and I was unable to see my family as they lived too far away, and I was living with my brain-damaged mother who was also grieving.

WOMAN AGED 18-30 WHOSE FATHER DIED OF CANCER ”

“ All support is aimed at white people. As an Asian Muslim I was constantly told by ‘support’ that I must be finding it hard to think about Christmas without my dad, but they totally bypassed Ramadan and Eid. Also there are huge cultural differences which are not acknowledged or supported.

A WOMAN IN HER 30S WHOSE FATHER DIED FROM COVID ”

While most people can be adequately supported by their friends, families and wider communities through a bereavement, some adults, children and young people will also need more formal emotional support, whether from a peer support group, a volunteer or a professional therapist. Those we heard from who received formal emotional or psychological support generally found it helped, providing a safe non-judgemental space to discuss their feelings and process their grief, and an opportunity to learn coping strategies to help them move forward in life and in their grief. However, we also heard many accounts of the difficulties that people faced getting the right support.

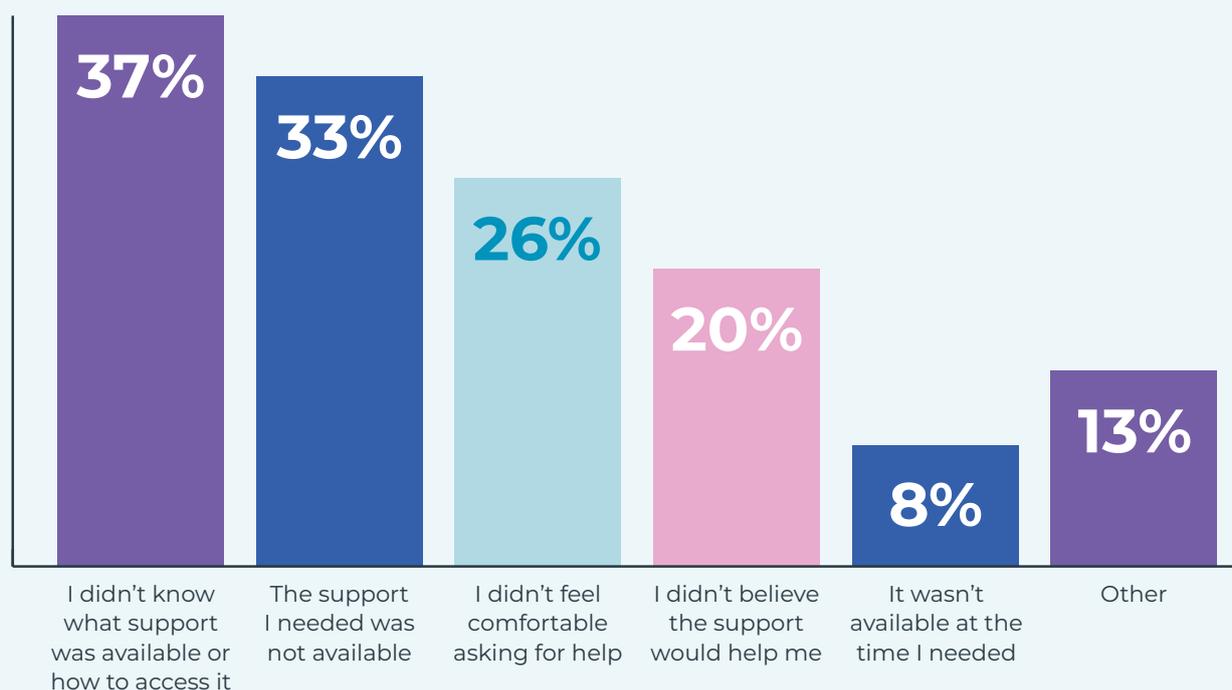
Key challenges for individuals accessing appropriate support

- **Stigma associated with seeking professional help**
- **Lack of awareness of own needs for support or what support is available**
- **Lack of proactive signposting to emotional support to cope with a bereavement.**
- **Lack of availability of support services**
- **Lack of support appropriate to individual needs (including age, ethnicity, religion and type of death)**
- **Support not available at the right time**
- **Support insufficient in length and duration.**

“ I had to search out support groups, I was lucky that my sister had a friend whose husband had died and she knew about these services but I would not have known if it were not through word of mouth.

WOMAN WHOSE HUSBAND DIED OF A HEART ATTACK ”

Barriers to accessing support from bereavement services (amongst those who wanted it) (n=281)



% Who Reported each Obstacle

It was well recognised, however, that some of the main barriers to access are outside of the control of individual services and reflect a lack of coordination, and inadequate funding, in the sector more generally. Organisations responding to the Commission identified a wide range of underlying challenges affecting their capacity to deliver optimal services that are responsive to the needs of the people they serve.

Key challenges affecting organisational capacity to deliver optimal services:

- **Squeezing of services from both sides in terms of increased demand and decreased funding**
- **Lack of statutory funding for bereavement services**
- **Patchy third sector and local authority grant funding impacting investment in, and sustainability of, services, leading to a postcode lottery of support**
- **Lack of appropriate training for supporting specific group needs (for example, ethnic minorities, people with learning disabilities)**
- **Lack of data on support need and service provision, locally and nationally**
- **Insufficient monitoring and evaluation**
- **Not enough collaboration and coordination between voluntary and statutory services, at a local or national level.**

There has never been enough funding for the bereavement support sector to meet the needs of bereaved people. It is almost wholly led by third sector and needs more government funding to make it sustainable into the future.

ORGANISATIONAL RESPONDENT



There is a need to raise awareness and understanding of the different types of emotional support available, to increase the amount of the support that is available, and to ensure that it meets the needs of diverse communities within the UK. This requires increased statutory funding, greater collaboration and coordination and increased awareness of the needs of different groups who are currently underserved. We are recommending the following changes to the delivery and commissioning of formal emotional bereavement support services.

Recommendations:

- 1 Bereavement services and support (including that provided by communities and faith groups) must sign up to an agreed set of standards, 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 emotional 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 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.



Conclusions and next steps



Throughout this report, and the evidence that contributed to it, we have seen how the impact of bereavement can be wide ranging, long lasting and profound. The COVID-19 pandemic has both exacerbated the difficulties people face through a bereavement and spotlighted them.

We have seen that we need to do more as a whole society to support all those affected by bereavement but taboos around grief, and uncertainties around knowing how to help, inhibit support throughout our communities – amongst friends and family, in our schools, colleges, and workplaces, and even among those whose job puts them in contact with bereaved people every day.

We have also seen that, 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. In addition, people affected by bereavement too 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.

The eight principles for change and the related recommendations that we have made, set out our vision of how to improve support throughout bereavement. Taken together they focus on equipping communities to support people through a bereavement; ensure better support and information at every touchpoint; and secure adequate and appropriate financial and formal emotional support to all who need it (see appendix 2 for full list of recommendations).

Achieving these changes will require concerted action throughout society, with strong leadership from those with the most power to enact change – those in national governments. 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**

CONT. »



- **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.

You can find out more about the Commission's work, and get in touch at www.bereavementcommission.org.uk



Appendices

Appendix 1: The Commissioners

The Right Reverend and Right Honourable Dame Sarah Mullally DBE, the Bishop of London (Chair)

Lesley Bethell is Chair of the Welsh Government's Compassionate Cymru steering group.

Simon Blake OBE is chief executive of the leading social enterprise, Mental Health First Aid England.

The Right Honourable Prof. Paul Burstow was the Liberal Democrat MP for Sutton and Cheam from 1997 until 2015. His most recent appointment is as chair of the UK's largest mental health service provider charity, St Andrews Healthcare.

Lesley Goodburn works as Experience of Care Lead for Provider Improvement at NHS England NHS improvement and also leads the Heads of Patient Experience (HoPE) Network.

Dr Donald Macaskill is the Chief Executive of Scottish Care. He is the chair of the Working Group of organisations which has produced Scotland's National Bereavement Charter for Children and Adults.

Professor Anand Menon is director of The UK in a Changing Europe and professor of European politics and foreign affairs at King's College London.

Zara Mohammed is the Secretary General of the Muslim Council of Britain (MCB)

Dame Barbara Monroe, DBE, FRSA was a British social worker and hospice chief executive. She is a Trustee and Senior Independent Director of Marie Curie, Vice Chair of the Royal Hospital Chelsea, Chair of Compassion in Dying and Chair of the Public Services Honours Committee.

Rabbi Baroness Julia Neuberger DBE is Chair of University College Hospital NHS Foundation Trust and Chair of The Whittington Hospital NHS Trust. She is Rabbi Emerita at West London Synagogue. She is a cross bench Peer in the House of Lords, and a founding Trustee of the Walter and Liesel Schwab Charitable trust. She is also a Trustee of the Rayne Foundation, Trustee of the Van Leer Group Foundation, and Chair of Independent Age.

Dr Marilyn Relf currently chairs the National Bereavement Alliance and is a member of the European Association of Palliative Care Taskforce on Bereavement and the International Working Group on Death, Dying and Bereavement.

Professor Nichola Rooney is a Fellow of the British Psychological Society, Chair of the British Psychological Society Division of Clinical Psychology NI, and leads on the NI Department of Health working group on COVID-19 Bereavement.

Julia Samuel is a leading UK psychotherapist and author of 'Grief Works' (2017) and 'This Too Shall Pass' (2020)

Dr Catherine Millington Sanders is a GP and the RCGP and Marie Curie National Clinical Champion for End-of-Life Care. She formed and chairs the RCGP and End of Life Care Partners Think Tank, supporting RCGP to develop end of life care focused resources.

Patrick Vernon OBE is Associate Director for Connected Communities at the Centre for Ageing Better, Equality and Diversity Adviser to Harrow Council, Chair of Citizens Partnership for Healthcare Investigation Branch (HSIB), Trustee of 38 Degrees, Non-Executive Director for Hertfordshire Foundation Trust, Senior Associate at OLMEC and an ambassador of the Almshouse Association.

Dr Idris Baker works as a Consultant in Palliative Medicine in Swansea and is National Clinical Lead for Palliative and End of Life Care in Wales. He chairs the Welsh National Bereavement Steering Group.



Appendices

Appendix 2: Full list of recommendations

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

- 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 should supplement funding for the transformation of bereavement support services set out in a later recommendation, 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, and co-produced with people with lived experience
- 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

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

- New legislation must require that all employers have a bereavement policy. Relevant government departments must publish guidance on minimum standards and best practice for large, medium-sized and small employers. This 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
- Statutory bereavement leave and pay entitlement of 2 weeks must be extended to encompass all close relationships
- 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

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

- 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
- Each UK Government must ensure that there is sustainable funding and effective delivery of palliative care services
- To ensure an integrated approach to delivery of care before, during and after a death, Governments across the UK must ensure that palliative and end-of-life care strategies are effectively linked to bereavement support strategies

CONT. »



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

- **Governments across the UK must legislate so that people can choose whether to register a death in person or online**
- **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**
- **Government departments and regulators must make sure bereaved customers are treated fairly and sensitively by working with relevant industry groups to develop minimum standards for death administration processes**

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

- **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**

...I have access to an affordable and meaningful funeral

- **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**
- **New regulations must be created setting out minimum standards for public health funerals**
- **Funeral Expenses Payment must be extended to currently excluded groups including students**
- **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)**

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

- **Entitlements to financial support following a bereavement must be extended to key groups including:**
 - » Bereavement Support Payment 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
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 - » 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)
- **All benefits for bereaved people must be up-rated annually in line with inflation in all four nations**
- **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**

CONT. »



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

- **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**
- **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**
- **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 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
- **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**
- **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**



 Follow the conversation @theukcb

The UK Commission on Bereavement works alongside the following organisations:



Supporting organisations:



Cruse Bereavement Support
Registered charity number 208078

Centre for Mental Health Charity
Registered charity number 1091156

Independent Age
Registered charity number 210729 (England and Wales), SC047184 (Scotland)

Marie Curie
Registered Charity, England and Wales (207994), Scotland (SC038731)

National Bereavement Alliance and Childhood Bereavement Network
Hosted by the National Children's Bureau, Registered Charity no. 258825