

Bereavement

is everyone's
business



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Dame Sarah Elisabeth Mullally
Bishop of London

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 in 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 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. formal

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 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.

+ Sarah Lonnin

The Rt Revd and Rt Hon Dame Sarah Mullally DBE

Background and Methodology

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.

Though bereavement and grief cannot be avoided, there are actions that can be taken to ensure that everyone who is grieving receives the support they need, at the right time. These improvements have never been more urgent.

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, leaving an estimated three million people experiencing bereavement. This translates to an estimated additional 750,000 bereavements across the UK.

As well as more people facing bereavement, the pandemic has had a profound impact on how those affected have experienced their loss. 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 had had a devastating impact. The lack of face-to-face contact from primary care and community-based services, and bereavement support services, has been difficult.

The COVID-19 pandemic has not only exacerbated challenges around bereavement, it has also spotlighted this universal human experience, and presented a rare opportunity to reflect as a society on 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 sector organisations, and with researchers Drs Emily Harrop and Lucy Selman who led an academic study on bereavement during the pandemic¹, an independent UK Commission on Bereavement through and beyond COVID-19 was established in June 2021 to investigate this key question in all four nations of the UK.

The Commissioners

¹ Details of this study and published papers can be found at covidbereavement.com

Chair of the Commissioners: The Right Reverend and Right Honourable Dame Sarah Mullally DBE, the Bishop of London

The Right Reverend and Right Honourable Dame Sarah Mullally DBE was awarded a DBE in 2005 for her contribution to nursing and midwifery. Prior to ordination, Bishop Sarah was Chief Nursing Officer in the Department of Health.



Following her training for the ministry, she served as a curate then Team Rector in Southwark Diocese from 2001 to 2012. From 2012 to 2015 she was Canon Residentiary and Canon Treasurer at Salisbury Cathedral before taking up her current role in 2015 as Suffragan Bishop of Crediton in the Diocese of Exeter.

Bishop Sarah has continued her interest in the health service having been a non-executive director at The Royal Marsden NHS Foundation Trust and then at Salisbury NHS Foundation Hospital. She is a member of the Council at King's College London University and a Vice President of Hospice Care Exeter.

Lesley Bethell is Chair of the Welsh Government's Compassionate Cymru steering group. She has retired and retains her interest in qualitative research with a special interest in healthcare and healthcare organisations, and a background in Sociology and Health Policy. Lesley is also a Bevan Commission Advocate, representing the views of patients and the public and working with the Bevan Commission to improve services in Wales.



Simon Blake OBE is chief executive of the leading social enterprise, Mental Health First Aid England. Prior to this, Simon was chief executive of the National Union of Students (2015 – 18), and Brook, the young people's sexual health charity (2006 – 2015). He has written about all aspects of Personal, Social and Health Education, and been a long-time campaigner for social justice including the rights of LGBT people. In 2011 he was awarded an OBE for services to the voluntary sector and young people.



The Right Honourable Prof. Paul Burstow was the Liberal Democrat MP for Sutton and Cheam from 1997 until 2015, taking a strong interest in social care, mental health and ageing. In 2010 he was appointed Minister of State in the Department of Health, establishing the Dilnot Commission, and holding responsibility for preparing the Care Act.

Since leaving parliament in 2015 he has been appointed Chair of the Tavistock and Portman NHS Foundation Trust; Chair of the Social Care Institute for Excellence; independent Chair of the Hertfordshire and West Essex Integrated Care System and, most recently, chair of the UK's largest mental health service provider charity, St Andrews Healthcare.



Lesley Goodburn has worked in patient experience and public and patient involvement for the last 10 years after a career in the customer service industry. She now works as Experience of Care Lead for Provider Improvement at NHS England NHS improvement and also leads the Heads of Patient Experience (HoPE) Network.

Lesley has shared her personal story of the death of her husband Seth via a film, a play and educational resources that explores the journey through the 33 short and heart-breaking days where they were both thrust into a world of palliative and end of life care. She works to raise awareness of signs and symptoms of pancreatic cancer, improve psychological support for patients and families given a late terminal diagnosis and improve end of life care.



Dr Donald Macaskill is the Chief Executive of Scottish Care, the membership organisation of providers of care home and care at home/housing support services in Scotland.

Dr Macaskill sits on a number of Governmental strategic and policy groups and has a particular interest in human rights-based approaches to care and support, personalisation, bereavement and palliative 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, having previously lectured at the University of Oxford. He is a regular contributor to The Guardian, an Associate Fellow of Chatham House, a member of the European Council on Foreign Relations, and Senior Associate member of Nuffield College, Oxford. Anand has written about his experience of bereavement during the pandemic for Tortoise.



Zara Mohammed is the Secretary General of the Muslim Council of Britain (MCB) following her service as Assistant Secretary-General of the MCB (2018-2020), helping lead on its ongoing COVID-19 response work from the outset of the pandemic and more recently, leading on the MCB taskforce that delivered the campaign against forced cremations of COVID-19 deceased in Sri Lanka.



Dame Barbara Monroe, DBE, FRSA was a British social worker and hospice chief executive. She was awarded a DBE in 2010 and is a Fellow of the Royal Society of Arts (FRSA). She held the position of Chief Executive of St Christopher's Hospice from 2000-2014, where she worked for well over 25 years.

Dame Barbara chaired the UK's national Childhood Bereavement Network for eight years, as well as serving as Honorary Professor at Lancaster University's International Observatory on End-of-Life Care, and Honorary Senior Lecturer at the University of Auckland. In 2017 she was awarded an honorary Sc.D. from Lancaster University and the Lifetime Achievement Award from the American Association for Death Education and Counselling.



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 was Senior Rabbi of the West London Synagogue from 2011 until March 2020 and is now Rabbi Emerita.

She is a cross bench Peer in the House of Lords, former CEO of the King's Fund, author, and a founding Trustee of the Walter and Liesel Schwab Charitable trust, set up in memory of her parents. She is also a Trustee of the Rayne Foundation, and Chair of Independent Age.



She chaired the Review of the Liverpool Care Pathway for Dying Patients in 2013 and was Vice Chair of the Mental Health Act Independent Review 2017-2018.

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.

Marilyn worked in palliative care until her retirement in 2019, developing one of the first hospice bereavement services at Sir Michael Sobell House, Oxford and contributing to the development of bereavement research and palliative care education. She is a founding Trustee of SeeSaw (a bereavement service for bereaved young people in Oxfordshire) and founded the UK Bereavement Research Forum, bringing together bereavement researchers and clinicians.



In 2017 Hospice UK awarded Marilyn the Ann Norfolk Lifetime Achievement Award for her contribution to the development of palliative and hospice care.

Professor Nichola Rooney is a Fellow of the British Psychological Society, Chair of the British Psychological Society Division of Clinical Psychology NI, and former Head of Psychological Services at the Belfast Health and Social Care Trust, with over 30 years of clinical practice in the NHS. Her extensive experience in bereavement includes recently chairing the British Psychological Society COVID-19 -19 Response to Bereavement and Care of Relatives workstream, and leading on the NI Department of Health working group on COVID-19 Bereavement.



Nichola is the current Chair of the Children's Heartbeat Trust NI; Honorary Professor at the School of Psychology, QUB; Senior Professional Advisor to the RQIA; Non-Executive Director of the Public Health Agency and Associate Consultant with the HSC Leadership Centre.

Julia Samuel is a leading UK psychotherapist. At St Mary's Hospital Paddington, she established the post of Psychotherapist for Paediatrics, where her role for 25 years involved seeing families who have children or babies who die, and training and supporting staff members. She now practises privately, seeing families and individuals for many different issues.



In 1994 she helped establish Child Bereavement UK and as the Founder Patron was heavily involved in many aspects of the charity's work. In 2016 Julia was awarded an MBE for her services to bereaved children and in 2017 Middlesex University awarded her an Honorary Doctorate.

Her books 'Grief Works' (2017) and 'This Too Shall Pass' (2020) were both Sunday Times bestsellers in the UK and Grief Works has been published in 17 countries.

Dr Catherine Millington Sanders is the RCGP and Marie Curie National Clinical Champion for End of Life Care, a role in which she is leading the design and development of new General Practice Core Standards for Advanced Serious Illness and End of Life Care, known as 'The Daffodil Standards'.



She Co-Founded the Social Enterprise Difficult Conversations. She is a practicing GP, bringing experience as a clinical commissioner, educationalist and a specialty doctor in palliative medicine. She formed and chairs the RCGP & End of Life Care Partners Think Tank, supporting RCGP to develop end of life care focused resources.

Patrick Vernon OBE has over twenty years' senior experience working across mental health, public health, heritage, and race equality in roles across the third sector, local government, NHS England, and for the Labour Party. He was awarded an OBE in 2012 for his work in tackling health inequalities for ethnic minority communities in Britain.



He is currently 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.

In 2020 he established The Majonzi Fund and co-founded BAMEstream to support Black and Minority Ethnic communities around support around bereavement and loss. Patrick is also a Patron of ACCI a black mental health charity in Wolverhampton, and of Santé a social enterprise in Camden which supports and befriends refugees and asylum seekers across London.

In 2019 he was awarded a lifetime achievement award for campaigning and advocacy work by the SMK Foundation. In 2020 Patrick was selected by British Vogue as one of Britain's top 20 campaigners and included in the 2020 Power List of 100 influential Black People in Britain.

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 National Bereavement Steering Group, established in 2020 by the Welsh Government to improve equitable planning and delivery of bereavement care, and is part of the team developing a new value-based national clinical programme for Wales.



The Steering group

The Commissioners are supported by a steering group made up of the voluntary sector organisations: Marie Curie, Independent Age, Cruse Bereavement Support, the National Bereavement Alliance, and the Childhood Bereavement Network, working in partnership with academic researchers: Dr Emily Harrop from Cardiff University, Dr Lucy Selman from the University of Bristol and Dr Catherine Grimley from the University of Warwick. The Commission is also supported by the charities the Centre for Mental Health, Sue Ryder and MacIntyre.



The Lived Experience Advisory Forum (LEAF)

While the Commissioners hold a wealth of professional experience of bereavement between them, the Commission's work has also, crucially, been guided at every stage by people with recent personal experience of bereavement. A Lived Experience Advisory Forum (LEAF) was established at the beginning of the Commission, made up of fourteen individuals bereaved within the last three years. The LEAF met regularly throughout the course of the Commission's work and by drawing on their own personal experiences helped to advise on the Commission's understanding and direction, as well as identifying priorities, challenges, and recommendations as the evidence was gathered and analysed. The LEAF members' commitment, generosity and strength has been of enormous value and the Commission is profoundly grateful for their individual and collective support.

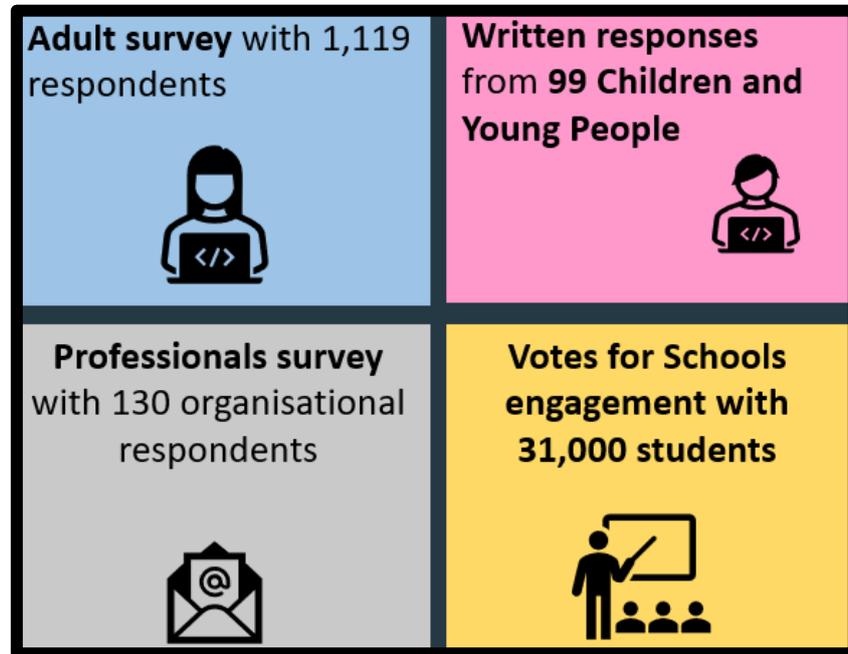
The Call for Evidence

Between Autumn 2021 and March 2022, the UK Commission on Bereavement heard from thousands of bereaved individuals, as well as organisations and professionals working with bereaved people, on experiences of bereavement and the support needs of bereaved people. Evidence was received by the commission both orally and in writing.

Written evidence:

An online survey of adults bereaved in the last 5 years was conducted between September 2021 and January 2022; 99 written responses from bereaved children and young people took place between November 2021 and February 2022; and an online survey of organisations and professionals working with bereaved people took place between September 2021 and January 2022.

In addition, the Commission engaged with 31,000 school and college students in classrooms through the organisation Votes for Schools in January 2022.



Oral evidence:

As well as the written evidence, the Commissioners heard oral evidence from experts on eight different topics:

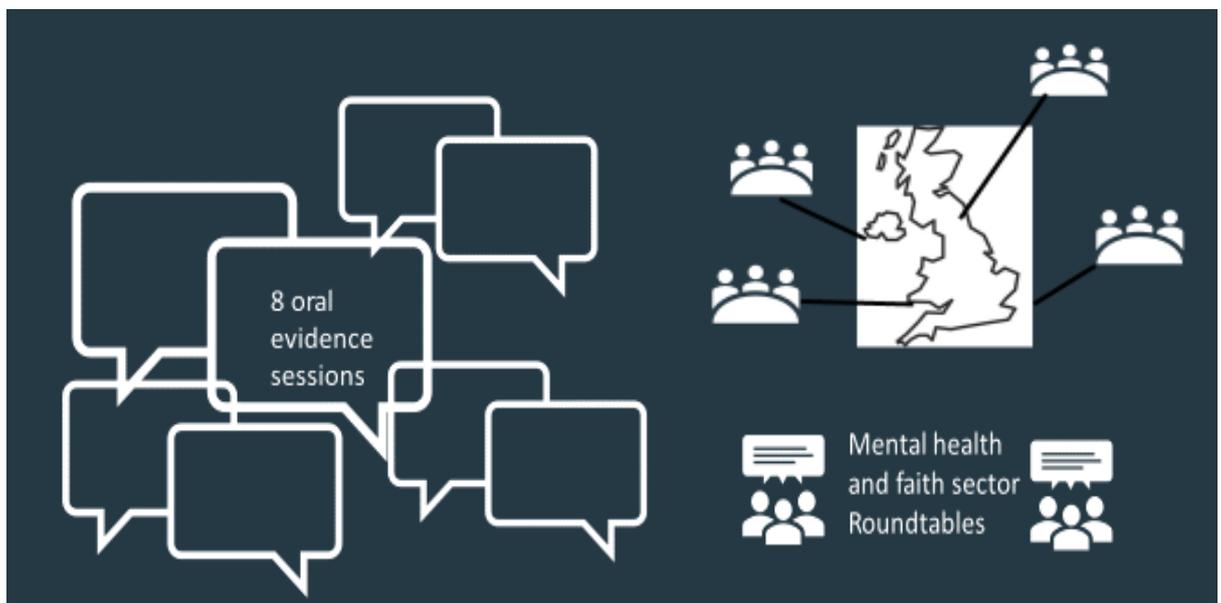
1. **Public Attitudes to Bereavement**
2. **End of life experiences**
3. **Financial Impact of Bereavement**
4. **Funeral Industry and Death Administration**
5. **Children and young people's experiences of bereavement**
6. **Older people's experiences of bereavement**
7. **Those underserved in the sector**
8. **Groups whose grief is disenfranchised**

Witnesses in the oral evidence sessions gave evidence predominantly from organisational perspectives, though some also shared personal stories. Organisations represented in the oral evidence included:

- Hospice UK
- John Taylor Hospice
- St Giles Hospice
- University Hospitals Birmingham NHS Foundation Trust
- Royal London Hospital
- London Ambulance Service NHS Trust
- Cardiff University
- Association of Bereavement Service Coordinators
- Quaker Social Action
- Macmillan Benefits Service

- Majonzi Fund
- Low Incomes Tax Reform Group
- The Society of Allied and Independent Funeral Directors
- The Death Management Advisory Group
- Cruse Bereavement Support
- National Bereavement Service
- Winston's Wish on behalf of the wider children's bereavement sector
- Grief Encounter
- Includem
- Family Rights Group
- Carers Trust
- Independent Age
- Age UK
- Time to Talk Befriending
- The Ubele Initiative
- Families, Friends and Travellers
- King's College London
- Kingston University
- St. George's, University of London
- Bristol Drugs Project/Homeless Health
- St Barnabas Hospice

Stakeholder roundtables were also held in all four nations of the UK, as well as with key representatives from the mental health and bereavement sectors, and leaders of different faiths and community groups.



Analysis

Qualitative analysis

All oral evidence sessions and stakeholder roundtables were audio recorded and transcribed professionally (verbatim). Responses from the online written consultations were downloaded into Excel files for cleaning, with duplicates and missing data removed before analysis.

The Excel files and word documents (transcripts) were then uploaded into NVivo, the leading qualitative analysis software used by academic and professional researchers across the UK, for analysis.

The analysis team used a thematic analysis methodology.² They developed a shared coding framework using an inductive approach and, once all the data had been coded, these codes were reviewed collectively to identify broader themes of significance. All evidence was anonymised before inclusion in the commission's findings.

Quantitative analysis

SPSS (v. 27)- a leading quantitative analysis software package used by professional social researchers and statisticians – was used to calculate overarching quantitative findings (descriptive statistics) and to conduct exploratory tests to determine whether there were any significant relationships between different topics asked about in the surveys (using Chi Square tests, One-way ANOVAs and Regression analysis as appropriate). "Statistically significant" relationships are ones we can expect to see in the wider population³.

Themes and findings from all strands of evidence – both qualitative and quantitative - were then synthesized to inform the report writing. The structure and chapters for the report were decided on collectively by researchers, members of the steering group and Commissioners after careful consideration of the key themes that emerged through the analysis.

Limitations

Due to the breadth of the Commission's scope and the decision to prioritise the timing of the publication, this report does not include a literature review. Instead, a scoping review that was conducted at the beginning of the Commission's work is attached in Appendix H.

The structure of the Commission's report

Analysis of responses to the commission showed the profound impact that bereavement has on every aspect of people's lives. The first chapter of the report reflects on the impacts of grief and bereavement that people shared with the commission.

The main part of the report – the following 9 chapters - then review what respondents told the commission about the key challenges faced by people affected by grief, and how decisionmakers can help improve bereavement support for the future. This part of the report is structured as a response to eight principles or "I statements"- which emerged from the analysis of responses to the commission, and which we want all bereaved people across the UK – our friends, family, neighbours, ourselves - to be able to say. (These principles are discussed in a little more detail in our vision for change on p23).

Each of the "I statements" has a corresponding chapter, exploring the challenges people told the commission they have faced in this area, what had helped address these challenges – and what had made them harder. Each chapter also makes recommendations for changes to improve support for the future.

² Braun V and Clarke V. Using thematic analysis in psychology.

Qual Res Psychol 2006; 3: 77–101.

³ It should be noted that "wider population" is limited to those in the population who are reflected in the demographics of this survey. Please see Appendix D for a full break down of the demographics of participants in the study. Also note that some tests were conducted on a subset of survey respondents, such as LGBTQ+ individuals, so are expected to be applicable only to that subgroup.



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

The final concluding chapter draws together these key findings and recommendations. Taken together these chapters show just how far there is to go to make a reality of the “I statements” set out above.

A table with the full recommendations from the commission can also be found in appendix A.

A summary version of the Commission report can be found online [here](#). We have also produced a 5-page summary of findings for the UK and each UK nation, an easy read version of the report, a report designed for children and young people and a translation of the summary in Welsh – all these reports can be find [here](#).

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

Almost all of us will experience bereavement in our life and each of us will experience it differently. A bereavement can be one of the most profound upheavals any one of us faces. As well as the direct emotional impact, a bereavement can create a wide range of practical challenges, which a bereaved person has to face, while trying to cope with their grief.

Before addressing the evidence about changes needed to better support those affected by bereavement, it is important to reflect on the experiences people shared with the commission about the impact of bereavement. This is the subject of this chapter.

Bereavement has happened through the ages, and common grief reactions and patterns of grief in adults and children have been extensively researched⁴. But the COVID-19 pandemic has spotlighted and amplified its impact. As well as more people facing bereavement during this time, the pandemic has had a profound impact on how those affected have experienced their 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. Feeling alone in their grief due to lockdown or having to shield or self-isolate had had a devastating impact. The lack of face-to-face contact from primary care and community-based services, and bereavement support services, has been difficult. This chapter introduces the evidence received by the commission about the impact of bereavement, including the impacts of the pandemic on people's experiences of grief.

A. Emotional impacts of grief

Respondents to the commission's survey talked about experiencing a wide range of emotions as a result of their bereavement, including shock, deep sadness, loneliness, anger and a sense of guilt around the circumstances of the death. The timing of the onset of grief varied based on the cause of death, with those bereaved by terminal illness with a longer prognosis describing anticipatory grief and loss. In addition, those who were bereaved of someone close to them suddenly experienced both acute and chronic grief.

‘It's really like a rollercoaster’ – 13-15 year old

Many respondents talked about feeling overwhelmed by sadness and devastation. Respondents described this in a variety of ways, including feeling lost or numb, feeling like their world had fallen apart, and some likened it to a bad dream, saying they didn't want to carry on.

⁴ <https://nationalbereavementalliance.org.uk/ourpublications/a-guide-to-commissioning-bereavement-services-in-england/>

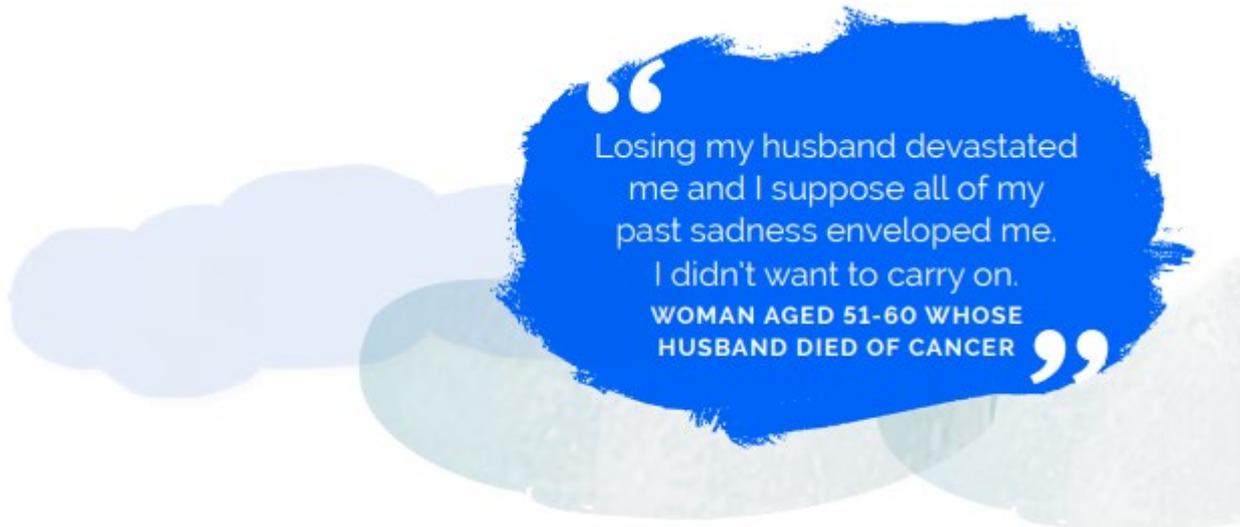
"It's awful, draining and it takes control of your life." – 13-15 year old

Respondents of all ages described the strength and changeability of their feelings, which could be overwhelming and feel out of control. The feeling of being on a rollercoaster, with emotions emerging unexpectedly, could make grief hard to manage over the course of the day. Specific triggers could be a problem, but these weren't always predictable.

"I felt like I was drowning -the waves of grief hit me so hard" - Woman aged 51-60 whose son died of COVID-19 (England)

"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

"It's very sad and I don't know when I will feel sad. Sometimes you just get upset in the middle of the day because you remember daddy has gone." – 5-12 year old



Manifestations of grief differed. Some young people expressed uncertainty about how to grieve and worried about whether they were doing it 'right'. As well as sadness, people of all ages talked about other feelings and reactions including anger. A number reported difficulty in concentrating. Some felt they couldn't enjoy or care about things anymore.

"As a person who doesn't sit down and cry I felt I was doing it wrong." – 16/17 year old

"I don't enjoy anything, I feel very angry a lot of the time." – 5-12 year old

Confusion about what had happened was also mentioned by children and young people.

"I don't understand why it had to be my daddy and why I can't see him anymore." – 5-12 year old

This emotional impact of bereavement had significant physical manifestations too. Respondents described experiencing tiredness and lethargy, an inability to focus, and headaches. Feelings of low energy were sometimes exacerbated by insomnia and changes in appetite.

"I had mind overload and I couldn't sleep." - Woman aged 51-60 whose son died of COVID-19 (England)

"I'm so tired all the time and I can't focus on things like I used to." – 5-12 year old

"It makes me sad and gives me a headache all the time." – 5-12 year old

'The loneliness was quite overbearing' – Woman in her 70s whose husband died of a terminal illness (England)

Loneliness was a dominant emotional experience in the individual evidence.

"It's a very lonely place to be." - Man aged 41-50 whose wife died of cancer, England

“We know grief is isolating, we know that from – that that’s true for everybody, for children and young people that might be particularly so.” – Children’s bereavement support organisation

Isolation and loneliness were sometimes as a direct result of missing the person who had died, including specific activities they used to do together. Among adults, the loneliness experienced directly due to the death of a close person such as a life partner was described as overwhelming.

“I’m very sad and upset. I miss my Daddy playing with me” – 5-12 year old

“At my age 78 the loneliness was quite overbearing”- Woman whose husband died of cancer, England

Feelings of isolation were magnified by feelings of difference. Some felt lonely even though they had people around them. There was a widespread perception that other people couldn’t understand the loss of a close person if they hadn’t experienced it first-hand and this barrier to empathy intensified loneliness. Among adults, this sense of emotional isolation was felt to be heightened when for atypical deaths: the death of a baby or child, a sudden or traumatic death, and when death occurred before society’s expectations of ‘old age’.

“I don’t think people really understand what it is like to be bereaved, many likening it to the worst relationship problem they know - a messy breakup or a long-term relationship or a divorce. “Oh you’re young, you’ll find someone new” is often heard. I’m not sure individuals can ever be taught this unless they have experienced this or witnessed it very closely” - Man in his 40s whose wife died of cancer (England)

“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)

“Very isolated but at the same time not alone. if you know what I mean.” – 13-15 year old

Similarly, some children felt they were the only ones this had happened to. Feeling different from their peers was a source of difficulty and distress.

“I felt like I was the only one who’s daddy had died.” – 5-12 year old

“It makes you feel different” – 5-12 year old

“It can feel like no one cares or wants to understand.” – 16/17 year old

Some young people experienced an unhelpful hierarchy of grief, which meant that their feelings and experiences were not recognised or validated by those around them, or that they worried this would be the case.

“Feeling as though because I wasn’t as close to them as other I shouldn’t grieve, so kept most to myself.” – 13-15 year old

“People invalidating young people’s trauma and upset does not help it leaves us feeling isolated and wrong for having big emotions and feeling equally distraught as some who knew them longer.” – 16-17 year old

In addition to this sense of emotional isolation, almost one third of adult respondents (28%) had no support from family or friends during their bereavement.

“Family zero friends zero community zero. Pretty much left to it with disabled children to manage.” - Man, 41-50, whose wife died (Scotland)

“It is the most lonely thing in the world. My family has never been the same or happy again.” – 13-15 year old

Children and young people also perceived that other family members tried to put a brave face on, increasing their sense of isolation.

“Very isolating and your family try to act like everything's okay and don't like bringing it up because it makes everyone upset.” – 13-15 year old

Additional stresses and impacts

Beyond the immediate emotional and physical impacts, survey respondents described how grief had considerable wider impacts on their everyday lives with their responsibilities becoming much more difficult. In some cases, respondents in employment or education described being temporarily unable to attend work or school, and bereaved parents described the difficulties of looking after their children, including supporting them around their grief, while grieving themselves.

“Supporting someone else with the bereavement, such as a minor ... has a huge impact on what is needed and how people cope.” – Woman in her 50s whose husband died of pancreatitis (England)

People talked about other stresses in the background which made their grief harder to manage. Some found the grief of those around them hard to witness, and this could inhibit them asking for support.

“It's hard to see my mum so sad all the time even when she's trying to be happy I can see the sadness as I feel it too.” – 5-12 year old

“Minimal support as my family were also processing their grief as well, however we were grieving together.” –16-17 year old

Other difficulties included expectations of behaviour, arguments, and troubles in the family. Even young children could be acutely aware of the financial impact on the family. Some had taken on new responsibilities to try and help their parents, including helping to sort affairs, and looking after younger siblings.

“I wish we had somewhere nicer to live and no money problems as this just makes things even harder for us.” – 5-12 year old

Families can face significant changes after a bereavement: a reduced income if the main income earner has died, along with other changes that children and young people have no control over including moving house and, sometimes, schools. . Being uprooted from friendship groups and known adults can disrupt support networks, and relevant information may not always be passed to the new school.

“I felt a lot of upheaval and change. My [family member] who looks after me had to go and look after my aunty and cousins. I felt left out and alone.” – 5-12 year old

“Moving from army life.” – 13-15 year old

“Children often move schools. These are again a kind of second shockwave of experiences that children have to manage which are very complex and very difficult for them.” – Children's bereavement support organisation

B. Longer term impact of bereavement

i. Adults

a. Employment

Adult survey respondents described difficulties moving through their bereavement and continuing with their work and life. Many described how the emotional impact of their bereavement meant they had to reduce their hours at work, change their job, stop working altogether, or taking early retirement if that was an option. For many this also impacted their financial wellbeing, leading some into debt or having to borrow money from relatives. The financial impacts and needs resulting from bereavement are more fully explored in chapter seven.

“I suffered PTSD and a breakdown and had to change my job to part time as I couldn't cope.”- Woman in her 50s whose husband died of a blood clot (Scotland)

“I was in full time employment but had to leave due to my grief. I have just started a florist from home.”- Woman in her 50s whose husband died of COVID-19 (Scotland)

“Due to the trauma and the effects it has had on my physical and mental health, I cannot work. This has caused me to go into debt.”- Woman in her 40s whose son died (England)

b. Adapting to new or changed roles

Over time, feelings of isolation tended to worsen as support dwindled from family and friends (discussed more fully in chapter three), while feelings of devastation remained, and individuals had to adapt to new roles and new family dynamics including in some cases increased caring responsibilities. These tended to exacerbate feelings of overwhelm and isolation.

“My father's death was unexpected and I had taken over his caring responsibilities for my mother. I was isolated and unable to cope, and I was depressed.”- Woman aged 18-30 whose father died of cancer (England)

c. Persistent emotional pain and impact on mental health

A dominant theme was the long-term impact of grief on emotional wellbeing, with respondents emphasising that the pain of bereavement never goes away, and in some cases, adults described pain getting worse after the initial few months as they were expected to get on with their lives without their loved one.

In exceptional cases, some described the long-term effects of PTSD caused by witnessing sudden, unexpected deaths; deaths by suicide; traumatic deaths, and deaths that left unanswered questions.

In the absence of the support they needed, some adults suffered from clinical depression and suicidal ideation following the bereavement.

“I'd have killed myself were it not for my children and my brother.” - Woman in her 30s whose partner died of alcoholism (England)

“It took 15 months to get the right therapy but which time I had PTSD and a plan to take my own life.”- Woman in her 40s whose father died of COVID-19 (England)

ii. Children and young people

a. Grief over time – developmental challenges

As with adult respondents, many children and young people talked about their grief lasting a long time. The expectation that they would ‘get over it’, or the experience of support falling away over time, was not helpful.

“Ongoing and difficult.” – 5 to 12 year old

“Horrible. My life will never be the same.” – 5-12 year old

“It would be nice for them to still support me even if it was more than a year ago, grief is not a linear process and it can still be very hard!” – 16-17 year old

“You will never get over it you will just learn to live with it.” – 13-15 year old

Many also described how their grief changed over time, with new feelings and difficulties emerging over time, often later than they or those around them expected.

“I felt more affected months after than right after the event.” – 16/17 year old

“Even though it may have happened a long time ago it still feels as though it were yesterday.” – 13-15 year old

“At the start I didn't want to talk about it and it hadn't really sunk in but I was getting let off for work at school when I was fine with doing it, but once it sunk in and I started feeling very overwhelmed by it.” – 13-15 year old

Organisations also shared the developmental challenges that children and young people faced. Younger children might not have the language and experience of life to express and process their overwhelming range of feelings and emotions. Many pointed out how children will revisit their grief as they mature emotionally and cognitively, and as the death takes on new meaning in their life. Families and services need to be aware of this to provide support that is appropriate to children's age and stage and acknowledges the long-term nature of their grief.

"Bereavement can impact children and young people in different ways, and at different times. Because children and young people struggle to manage the enormity of grief all at once, their bereavement 'period' can appear shorter. However, this does not mean that they have dealt with the bereavement, and the effects can manifest in different ways throughout the course of their lives." – Children's bereavement support organisation

Bereavement can also bring longer term risks to children and young people's outcomes. A small number of young people did discuss how they felt their bereavement was impacting on their life choices and chances. Organisations mentioned particular risks associated with bereavement around the time of transition to adulthood, and spoke of the overrepresentation of bereaved young people experiencing homelessness, substance misuse or involvement with the criminal justice system.

"Those transitional ages for young adults when they are dropping out of universal services they are not in contact with schools. This is a real gap ... and actually how do we capture these young people and it really affects their life long chances, homelessness, ...substance misuse, potentially going to prison, street sleeping." – Children's bereavement support organisation

The oral evidence heard by the commissioners revealed that many young people in youth offending institutions had suffered bereavements and received inadequate support.

"I have worked in mental health for a very long time, 25, 30 years. And... you can't doubt the impact that loss has on people's mental health, both in terms of generic mental health services, but also particularly in the criminal justice pathway." – Stakeholder roundtable

"...about 20 years ago I did a piece of work on the youth, juvenile youth offending estate, I don't know if that's the right language or it's bad language, but it's the language which was used at the time, I think. And one of the things that really struck me was how many of the young people in those institutions had been bereaved without the adequate support through and had never been in contact with mental health services, but somehow they'd ended up in criminal justice estate."

As well as the cognitive aspects of bereavement, there were ways in which children and young people's social positioning and power made their experiences differ from those of adults. Organisations pointed out how bereavement could affect children's sense of control over the world.

"Everything has fallen apart and with that their control." – Children's bereavement support service

Factors that may increase the risk of more complex grief

Organisations and individuals shared that the circumstances around the bereavement can impact on experiences of grief. The issue of prolonged or complicated grief, and the need for support to be made available where this occurs, was mentioned by several respondents.

Identified risk factors for prolonged emotional pain or complicated grief included:

of death

Some examples of unexpected deaths shared in the evidence included COVID-19 deaths (20% of survey bereavements), sudden deaths of children and babies including miscarriages, stillbirths and sudden infant death syndrome (4% of survey bereavements), accidents (3% of survey bereavements), deaths by suicide (3% of survey bereavements) and deaths by terminal illness with a late diagnosis (total % unclear).

Bereavements due to COVID-19 or accidents did not result in statistically significant differences in rates of formal support desired or accessed⁵, but the quotes below highlight how bereavements from these causes can still lead to trauma and complex grief.

“The brutal suddenness of being made aware a tummy ache at 6.00am was terminal at 5.00pm on the same day and death 12 hours later.” - Man aged 90+ whose wife died of ischemia (England)

“Just couldn't cope. The shock was so immense.” - Woman 71-80 whose daughter died of an accidental overdose (England)

“After the shock visit [being informed of accident by police] I may have tried suicide. My other son did.” -Woman in her 40s whose son died in an accident (England)

“A COVID-19 death it is unlike any other experience of death and grieving.” -Woman in her 40s whose husband died of COVID-19, Scotland

“For deaths that are sudden and unexpected, those bereaved are at risk of developing traumatic and complex grief reactions and need access to specialist bereavement support as soon as possible after a death.” – organisational respondent

Where a person has a 'good death', some respondents felt that this can be a comfort to bereaved people. A death which doesn't meet our current expectations around full meaning and explanation – for example, feeling that the person suffered unnecessarily, or being unsure about they would have wanted at the end of their life - can cause feelings of guilt and uncertainty. Respondents also reflected on the importance of conversations about death and dying in advance to help them prepare.

“It can be difficult to start conversations about end of life and ageing, but when people feel the person who died had a good death, this can make the process of grieving easier. Our November 2021 research found that some older people reflected that when the person who died had had a positive end-of-life experience, this had brought them some comfort. ‘So, the end of her life was kind of the way that she'd wanted it. That makes sense and that's the most important thing. So, we'd put in place all the things that were important.’” – organisational respondent

“Talking about death and dying in advance – not just after death – is critical. It can help someone to process grief if planning and conversations are had in advance, even if this is as informal as conversations about funeral music choices. Difficult decisions, for example those around place of death and funerals, can be eased if conversations have been had over what dying well looks like to people.” – organisational respondent

umstances

Organisational respondents shared a range of additional factors which they felt could contribute to a higher risk of complex grief. These included:

- Difficult family backgrounds and relationships, including difficulties in childhood such as conflict or emotional or physical abuse
- Social isolation or loss of a support system
- Past history of depression, separation anxiety or post-traumatic stress disorder (PTSD)
- Other major life stressors, such as major financial hardships (these are called 'concurrent stressors')
- A history of difficult bereavements

- Those in kinship care or the care system
- Children from minoritized groups

⁵ $p > .05$

Organisations also reflected that prolonged or complicated grief was more likely for those on a lower income (and more likely during the pandemic). Financial hardship was identified by organisations, including not knowing how to pay the funeral bill.

“Research confirms that lower income groups are at higher risk of experiencing complicated or persistent grief and this is partly because they face more difficulty accessing appropriate services, information and time off to help them cope with grief.” – organisational respondent

“I looked at 100 referrals. And what was really characteristic of these referrals is ...they had a combination of risk factors. So the combination was of a more difficult, this is in a hospice setting, a more difficult than usual death with traumatic aspects to it. Where there were difficult family backgrounds, so either isolation or a lot of family conflict, a lot of disagreement, the family not really pulling together to support each other. And a personal history of difficult bereavements or drugs, alcohol problems, being abused either emotionally or physically in childhood, a lot of problems with attachment. So it was a combination of those factors that created the complexity and the need for our sort of highest tier three type of intervention.” – organisational respondent

Respondents also highlighted other personal circumstances which they felt could make grief harder including: being a young widowed parent, having to juggle new caring responsibilities as well as supporting children through grief; experiencing multiple bereavements at the same time; being an older carer; ageing without children; and people with dementia or learning disabilities.

“I became a young widow with 3 young children suddenly, following the RTC [road traffic collision] that killed my husband. The devastation was unimaginable. I did not feel I got the adequate support on how to help my children as their mother.” - Woman, in her 40s who whose husband died in a road traffic collision, England

“In our experience with the older people we have been supporting, they have actually had the experiences of multiple people dying throughout the years and they haven’t had any support or have gone through those traumas. So when bereavement happens in their later years, you know, all of these things are impacting all their experiences that have gone before and it’s not just the loss that they are experiencing at the time of the person that has just died.” – organisational respondent

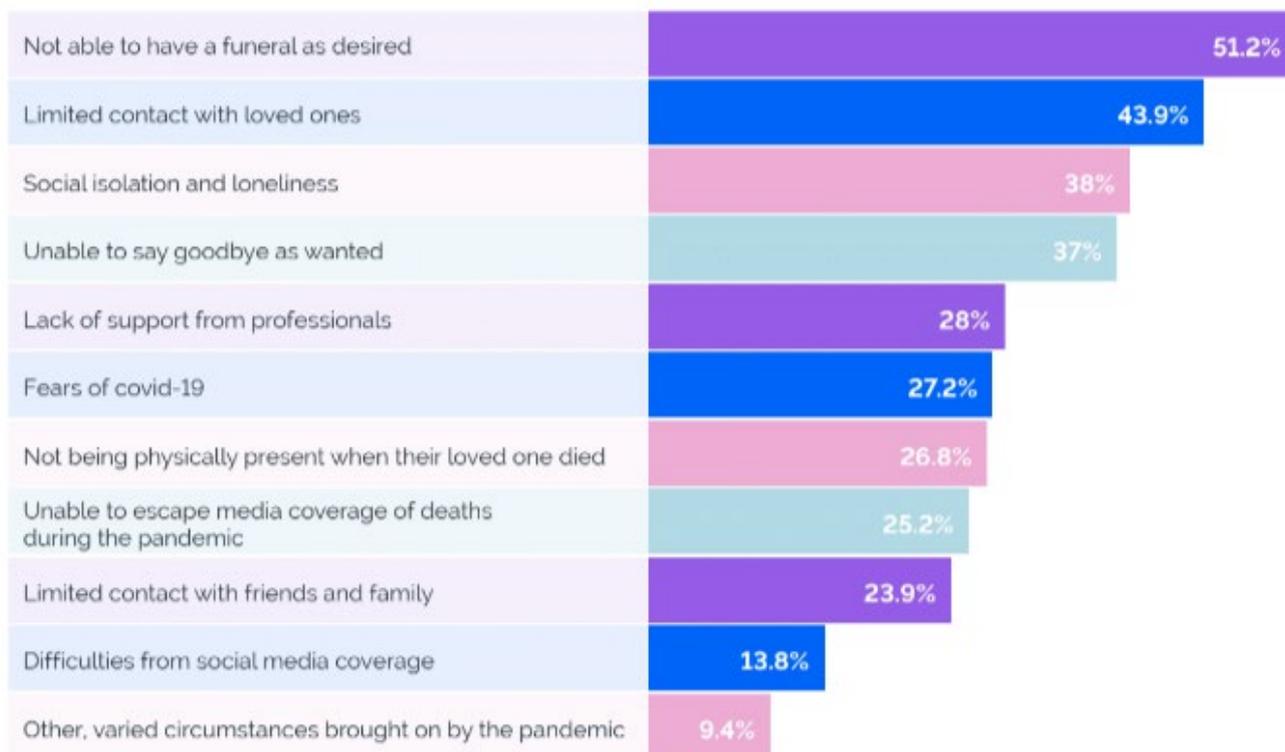
19 pandemic

Both the individual and organisational evidence confirmed that the COVID-19 pandemic had profound and largely negative impacts on people’s experiences of grief and their support needs.

68% of adult survey respondents confirmed that the bereavement experience they wished to talk about occurred during the recent pandemic. Respondents were then asked to share difficulties they had experienced due to this, with more than two thirds responded that they had gone through three or more difficulties.

The graph below shows the proportion of adults affected by each difficulty – with over three quarters affected by not being able to have the funeral or wake they wanted.

Prevalence of difficulties amongst adults bereaved during the COVID-19 pandemic



Note. The chart represents responses from 757 adults.

Young people were also asked how COVID-19 had disrupted their grieving process, and they struggled in similar areas to adult respondents.

Organisations reflected that the pandemic resulted in greater need for bereavement support services for a number of reasons – including greater numbers of people who had been bereaved, with more complex need. There was a recognition among participating organisations and professionals, that many people may not have presented to formal bereavement services due to wanting to wait until the pandemic was over. Yet without the right support, there will be long term consequences for people bereaved during COVID-19, including around mental health, education, work, relationships/families, finances, housing and within communities. *Bereavement during COVID-19* is an extensive national academic study, exploring many aspects of bereavement during the pandemic in depth.

“I think that the uncertain part is that if people don’t receive the right support for them now and in the future then there will definitely be these long-lasting effects. Whether it’s education, work, relationships, finances, housing and their impact on their families and also within our communities.” – Organisation in the England roundtable

Bereavement during COVID-19

This national study ([COVID-19bereavement.com](https://www.covid-19bereavement.com)) led by Dr Emily Harrop from Cardiff University and Dr Lucy Selman from the University of Bristol aims to investigate the grief experiences, support needs and use of bereavement support by people bereaved during the pandemic in the UK, and the adaptations, challenges and innovation involved in delivering bereavement support. The research team are using a combination of qualitative and quantitative research methods, with funding from UKRI via the Economic and Social Research Council.

Papers exploring a range of different aspects of bereavement are published on the website.

Increased trauma, feelings of anger and anxiety, in addition to loneliness and isolation, were all mentioned in association with pandemic related bereavement, as was prolonged grief. These were exacerbated by witness to mass bereavement, with updates and daily death tolls being reported across all sections of the media.

Over a third of adult survey respondents bereaved during the pandemic (37%) said they had difficulties not being able to escape media coverage of deaths during the pandemic, while 20% cited difficulties relating to content on social media. 8% of the children and young people we heard from said they had been affected by media coverage of deaths during the pandemic while a further 8% mentioned social media. In some cases, mass bereavement meant people felt robbed of their individual grief experiences.

“Reliving it every day as COVID-19 is on the news daily.” – Woman 41-50 whose husband died of COVID-19, (Scotland)

“I feel abandoned by all, my mum’s death certificate says COVID-19 but deniers tell me it wasn’t COVID-19, social media screams cover up. People say we’re done, it’s over, we can move on. COVID-19 killed mum, destroyed my life, I can never move on.” – Woman 51-60 whose mother died of COVID-19, (England)

The trauma around deaths during the pandemic – relating both to the often sudden, unexpected and distressing nature of deaths by COVID-19, and to the impact of restrictions on bereavements by all causes, was emphasised by both individuals and organisations.

The pandemic had also reignited previous losses as well as increasing anxiety that others would die.

“Bereaved children have become particularly afraid of further bereavement, that someone else they love may die by suicide because things are so difficult, or that they will lose loved ones to COVID-19 or otherwise.” – Children’s bereavement support organisation

Organisations described how all children and young people have been confronted by death and dying during the pandemic in an unprecedented way. Some organisations described how we don’t yet know the full impact of being bereaved during the pandemic on children and young people.

“Children have been surrounded by discourse around death and dying around the last 18 months or so which is probably unprecedented and again that requires some kind of response from us.” – Children’s bereavement support organisation

“We feel that there is a very long tail to this. We don’t really know what the impact will be on children and young people, either those bereaved through that period potentially through COVID-19 death or actually bereaved of a parent or a sibling or someone close to them through something else.” – Children’s bereavement support organisation

Even among people who had been bereaved prior to the pandemic, the pandemic had heightened some people’s feelings of trauma related to earlier bereavements. One organisational respondent noted an increase in suicidal ideation in the general population during the pandemic:

“The pandemic particularly exacerbated the feelings of hopelessness, isolation and loneliness in people who are bereaved.” – organisational respondent

“PTSD caused by the horror of having to witness, via a video call, my dad dying in agony and distress and being unable to comfort and support him.” – Woman in her 50s whose father died of COVID-19, England

“Bereavement and grief are impacted by the cultural context in which they happen. This research demonstrates clearly that the cultural context of the pandemic meant many of the profoundly social experiences pertaining to death, grief and mourning were regulated, restrained and prohibited during this particular epoch, effectively shaping and changing contemporary bereavement norms. Consequently, we have to fully understand the ways in which the pandemic

*shaped these norms, in order to learn from them and better prepare for the future.” –
organisational respondent*

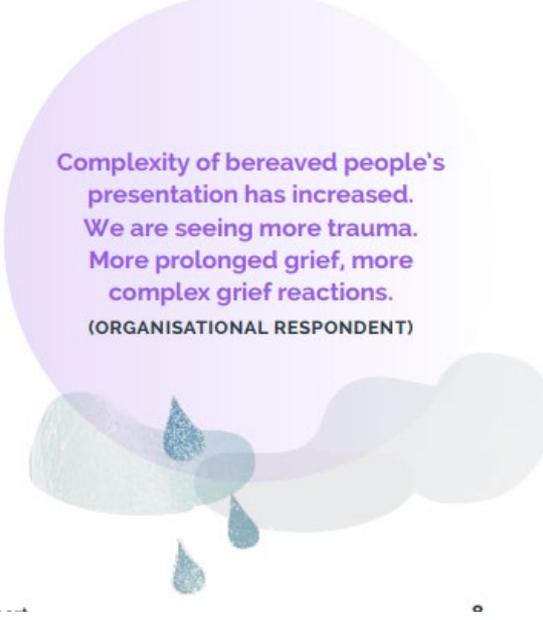
Impacts of grief: **Key points and conclusion**

As shown in this chapter, the impacts of grief are both intense and wide ranging, touching all areas of life. The emotional impacts of grief are varied and changeable over time, crucially, often lasting for many months or years in different forms. Grief impacts all aspects of people’s lives, with physiological impacts; financial impacts; practical impacts on work, school and home life; and even impacts on people’s longer-term outcomes.

While most people are able to continue with their existing responsibilities some time, for some people intense emotional pain does not go away.

There is also clear evidence that the COVID-19 pandemic and lockdown restrictions had a significant impact on people’s experiences of grief, as well as the number of people who are bereaved, increasing feelings of pain, isolation, and trauma.

In the following chapters we will move on to the key question for the commission – what can be done to improve support for the future.



Complexity of bereaved people's presentation has increased. We are seeing more trauma. More prolonged grief, more complex grief reactions.
(ORGANISATIONAL RESPONDENT)

Our vision for change

People shared lots of inspiring examples with us about how compassionate people and sensitive systems meant that their grief, while tough, was manageable.

Sadly, our evidence also showed many examples of when grief was made more challenging by people who didn’t know what to say, systems that were difficult to navigate, and organised support that simply wasn’t available or suitable. These examples – both good and bad - have given us a clear vision of the things we want to be in place for all grieving people, wherever and however they have been bereaved.

When we say all grieving people, it’s important to remember that over time, that will include almost all of us. Over the course of our life, most of us will experience the death of several people who are important to us. There are times in our life when we are recently bereaved or when it is a key part of our identity and life story, and other times when our grief is more in the background.

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. We look forward to working with you to make these happen.



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

As we saw in the previous chapter, 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.

However, as responses to the commission showed, too often such support is absent. Sadly, this has been particularly true over the course of the pandemic where infection control measures have meant that many people have had to remain “physically separate” from family, friends and communities following a bereavement, and – as the quote above shows - they were “emotionally separated” too.

This chapter explores experiences of support from family, friends and communities. The first section explores the levels of support survey respondents told the commission they received; the second section explores positive examples of support; the third section identifies barriers to support, and the final section outlines suggestions and key recommendations for change.

Key findings:

- **Over a quarter (28%)** of adults received **no support from family**, **almost half (46%)** received **no support from friends** and nearly **one in five (18%)** received **no support from any informal source** (family, friends, faith communities or co-workers).
- Adults, children and young people highlighted the importance and value of the support they received from friends, relatives, neighbours and faith communities following their bereavement. Many said they could not have coped without it.
- Of those who had received community support, it was most common to be supported by family members (72%) followed by friends (53%) and faith communities (11%)
- Practical and emotional support were both seen as very important to bereaved people
- **Barriers to support** from friends, family and communities included:

- Ongoing **taboos** around dying, death and bereavement
- **poor understanding of grief** including how long it can affect someone
- **low awareness of how to support someone bereaved**
- **stigma** around certain types of deaths
- **regional disparities** in community initiatives
- **Suggestions for change** identified by respondents included:
 - Grief education
 - Initiatives to normalise conversations about death, dying and bereavement and advance understanding of grief

Alan's story

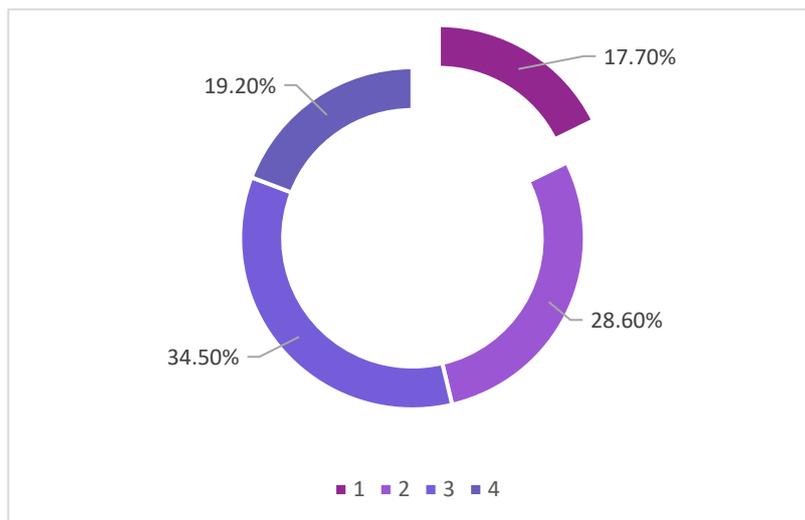
Alan is 52 and his wife Laura died a year ago from liver disease and sepsis. He lives in Liverpool with his son and daughter (15 and 12).

*"[Support from family and friends has been] very hit and miss, **some only lasting until the funeral**. False promises from some and lack of empathy as if I should of moved on or got over it already.*

*A few [friends] have been the best but one in particular is **going through the same thing starting at a similar time so knows** and has been very helpful."*



A. Sources of Support



Note. The chart represents responses from 1,119 adults.

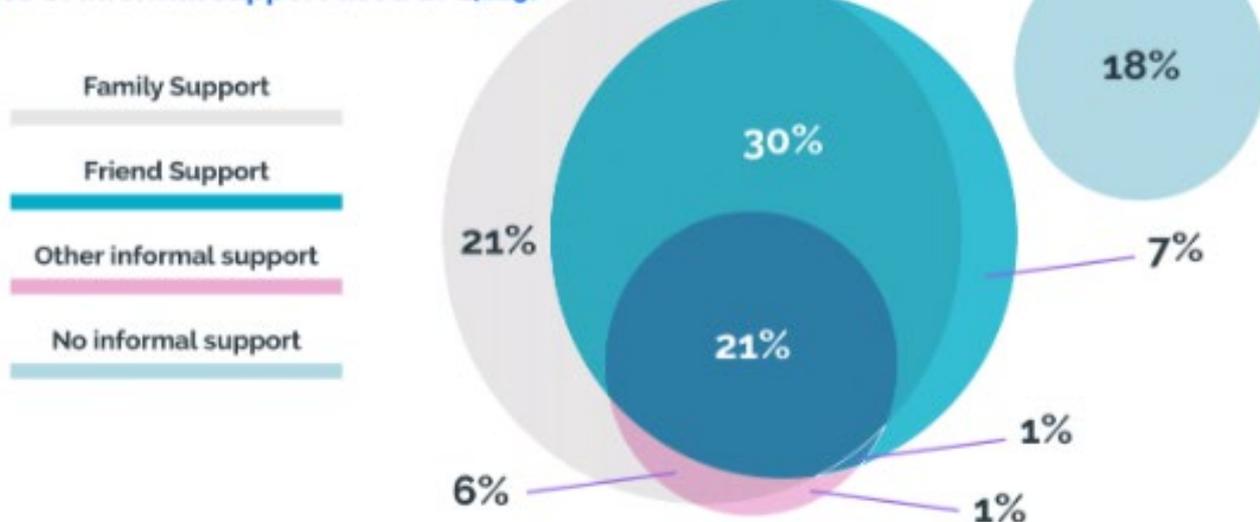
Respondents were asked if anyone had provided them with support which helped them to cope with their bereavement and given a list of 12 potential sources of support, which also included options for “no one” and “other.” Some respondents selected multiple sources of support.

Most people were supported by relatives or friends, with 72% of respondents reporting they received support from a family member, 53.3% received support from a friend and 11.3% receiving support from a faith community.

However, almost **one fifth received no support from any informal source (17.8%), a third of adults 28% received no support from family, and almost half (46%) received no support from friends.**

Base: 1119 adults

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

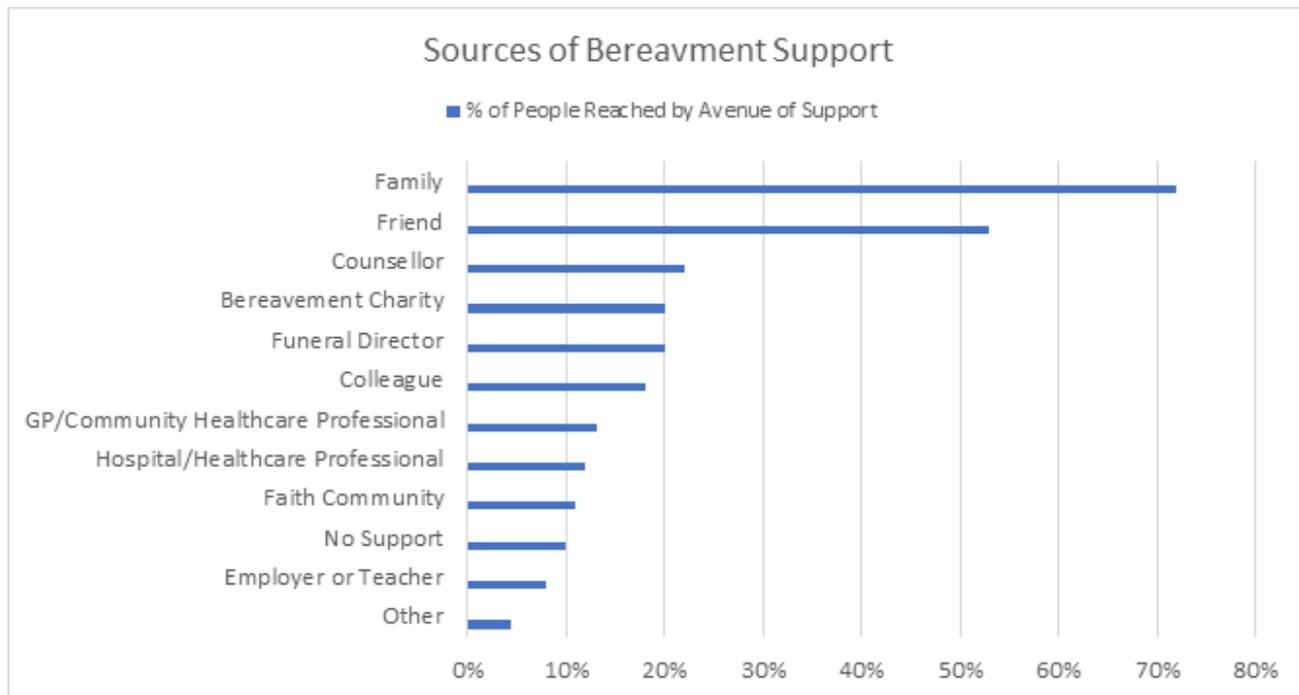


B. Relationship Between Informal and Formal Support

The support options could be broadly divided into informal sources of support and formal support from professionals. Informal support was regarded as support from friends, family, faith community, colleagues, and employers/teachers. Analysis was conducted to determine if the amount of informal support a person had was

related to their access to formal support. A relationship was found¹ showing that, for each additional type of informal support someone had, they were 1.23 times more likely to access formal support services.

There are several potential explanations for this relationship. First, it is possible that people who needed a greater amount of support received it from both informal and formal avenues. It is also possible that those who had greater informal support were more empowered and informed through that support to access formal support when it was needed.



Note. The chart represents responses from 1,119 adults.

What helped

Adults, children and young people highlighted the importance and value of the support they received from friends, families and pets following their bereavement. Many said they could not have coped without it.

Organisational respondents also stressed that social support is important for people experiencing a bereavement. For most people who have been bereaved, the support of family, friends and their wider community is all they need. Some respondents cautioned against the ‘medicalisation’ of grief, such as implying that formal support such as counselling is always necessary.

“Friends and family are key and will get most people through without formal external support.” – organisational respondent

A. Practical support from family, friends and the community

For bereaved adults, practical support was related both to the administrative tasks associated with bereavement, such as informing companies and banks and helping with funeral arrangements, as well as more general tasks such as delivering food and helping with chores around the house.

“If it wasn’t for my son taking over everything I couldn’t have coped. I didn’t know how to do anything, my brain just died.” – Woman in her 70s whose husband died of old age (England)

“Friends did practical things like walking the dog, making us food, helping sort music for the funeral in a format the crematorium needed” – Woman in her 50s whose parents and a grandparent both died (England)

Parents identified **practical support** as being particularly helpful – meals, financial support, help with childcare, lifts and opportunities to have fun.

“Friends/family taking her on days out.” (Parent of 5-12 year old)

“Helped with shopping when we're struggling.” (Parent of 5-12 year old)

People of all ages also reported that **keeping busy and doing normal activities** helped them navigate their experiences of bereavement, distracting them as well as connecting them to others.

“My friends playing with me at school” (5-12 year old)

“I did activities like cooking and drawing to help stay busy”. (13-15 year old)

“A dog and walks everyday certainly helps, being stuck Indoors is not good. So grateful to my pet Murphy” man in his 60 whose wife died of a terminal illness and also a friend (Wales)

For many people, the impact of lockdown restrictions meant that it was harder to engage in activities that could distract them from their grief.

“Trying to find other things to plough energies into and distract myself, walking, gardening e.t.c. I'm normally a very social person so had to find other ways to channel my grief which wasn't easy.” -Woman in her 30s whose daughter and grandparent both died (Wales)

What helps: Practical support

- Help with everyday tasks such as shopping, cooking, cleaning, walking the dog
- Help with funeral preparations
- Help to keep busy with fun and enjoyable activities

B. Emotional support from family, friends and the community

Adult respondents described the crucial emotional support they received from friends and family, included loved ones “checking in” regularly, acknowledging the death, and being there to listen or to talk.

“Family and friends have been faultless in their support. I have received messages of support and kindness that are not overwhelming and have continued throughout the weeks since his death. I have felt very fortunate to have so much kindness sent my way” -Woman in her 30s whose husband died of a cardiac arrest (Wales)

“Family and friends wrapped me in care, were there to help in any way I needed. And still check in on me too”. -Woman in her 60s whose husband died of pneumonia and complications from other illnesses

Families, both immediate and extended, friends and other trusted adults, and the wider community were seen as vital supports for bereaved children and young people. Children and young people wanted people to check in on them over time, listen, support and ‘be there’ for them, advocate for them, help them to understand they are not alone, and do normal and relaxing things with them. They wanted opportunities to talk, but no pressure to do so. Children and young people told us they also valued support from those close to them who understood what was happening and were ready to help as and when needed by being there, listening without judgement and offering ongoing support.

“Aunts, cousins & friends have been available so she has someone to talk to or confide in other than me as her parent”. (Parent of 5-12 year old)

“It helped to write all my feelings down onto paper and show my mum to show her the way I felt.”(13-15 year old)

“The friends who weren't scared to acknowledge his death [helped].” (Parent of 5-12 year old)

Being able to talk freely and without judgement to understanding family members and friends was mentioned several times by people of all ages. It was important for individuals to have their feelings and emotions heard and validated.

“Listening to me and then validating feelings without trying to “fix me”.” Woman in her 40s whose husband and father-in-law both died (England)

“Mummy giving me lots of cuddles and letting me talk”. (5-12 year old)

“[What] I find most helpful is when people ask me about my story or listen to stories about my dad or ask about him.” – Woman 18-30 whose father died of an accident, England

“I'll never for a second forget that I had my beautiful girl for 35 years, and it invalidates her life when people close down a conversation about her out of embarrassment” – Woman in her 50s whose daughter died of cancer, England

Where family members and friends shared their own similar experiences, this had sometimes been particularly helpful. Respondents described how this enabled them to feel less alone, better understood, and well supported with valuable advice.

“A close friend was exceptionally supportive. She had herself lost her husband 5 years earlier, so just got it.” Woman in her 50s whose husband died of heart disease, England

“A few have been the best but one in particular is going through the same thing starting at a similar time so knows and has been very helpful” Man in his 50s whose wife died of sepsis and liver disease, England

Contrastingly, many young people expressed ambivalence about talking about the person who had died when they didn't want to do this and being reminded of their painful loss when this wasn't welcome. Some had been given advice they found unhelpful, or been pressed to talk when they didn't want to.

"Having other people offering useless advise that I didn't want or need." – 16-17 year old

"I don't like people mentioning him." – 5-12 year old

"People would often talk about it too much and I didn't get much time to think about it on my own or just relax on my own." (13-15 year old)

C. Support from the local community

Neighbours

Some survey respondents of all ages described how support from beyond their immediate family and friendship circle was also appreciated. The neighbours, or other local people who reached out to check in with bereaved people beyond the immediate impact of bereavement, was also noted.

"People have been extremely kind and supportive, and generally very understanding and empathetic" (16/17 year old)

Survey respondents spoke of valuing the opportunity to talk about and remember the person that had died with those that knew them among their community.

*"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 (England)*

What helps: Emotional support from family, friends and the community

- Acknowledging the death
- Showing kindness
- Being there to listen without judgement – but not forcing conversations
- Being with people in their pain – not trying to fix it
- Sharing positive stories of the person who died

Faith communities

Many people with a religion reported benefitting from support from their local faith group or place of worship. As well as the social aspect and opportunity to talk, they valued the safe space for private prayer.

"I have a circle of friends in my faith community who have been brilliant, with frequent walks, conversations, phone calls and visits, as well as offers of help" Man in his 60s, whose wife died of a stroke (England)

"I received great support from family, friends and faith community over the past year. This support ranged from phone calls, meeting up for coffee, offers of prayer support" – Man in his 60s whose wife died of a terminal illness (England)

“My local church opened twice a week for private prayer and it gave me a safe space to grieve and a reason to leave the house.” - Woman in her 30s whose baby was stillborn (Wales)

Respondents described how faith communities had provided valuable support both in practical assistance, including ministry tasks, and in some instances facilitating access to more formal emotional bereavement support through religious communities.

“Our church were great too, taking ministry tasks off us so we didn't have to do them.” - Man in his 30s whose son died of a terminal illness (England)

“Church cooked us meals. Our vicar & his wife allowed our family to move in with them for some time.” - Man in his 40s, whose son died of suicide (England)

“I have been able to access amazing programs, educational and cultural, set up by my faith community almost overnight – Woman in her 60s, whose father died of cancer (England)

Informal networks and groups

The evidence provided by organisations to the commission highlighted networks of support that are already available in some communities with the success of initiatives such as death and grief cafes, bereavement walks, and compassionate communities. Organisations described how these projects help to normalise the conversation around death, dying and bereavement as well as bringing people together to share their experiences and have an opportunity to talk. They also play a role in signposting people to other types of support. Individuals in the adult survey expressed positive views of these initiatives and movements, though most did not have first-hand experience of them.

“All initiatives that encourage open discussion about death and bereavement should be encouraged. The Death Cafe movement is a brilliant way of bringing the subject into the open.” – Woman in her 50s whose husband died of COVID-19, England

Organisations highlighted that wider community activities such as walking groups and coffee mornings can be equally as helpful, if not more helpful than formal bereavement support, with the additional benefits of combatting loneliness and isolation.

“The hospice runs a monthly walking club for bereaved people. More of these in local communities would be good - gets you out and active and allows you to talk.” - Woman in her 50s whose mother died of a terminal illness (England)

Local initiatives

Dudley Bereavement Charter was mentioned in the organisational evidence as a positive example of an initiative developed by a local authority in partnership with local organisations. The charter sets out a vision of shared values and behaviour for the people of Dudley.

The organisational evidence also identified the Death Positive Libraries initiative, although this was not mentioned by any individuals who shared evidence which indicates it is not widely known about.

D. National public awareness campaigns

There was broad support in the individual evidence for all initiatives that help to break the taboos around death, dying and bereavement, increase death and grief literacy and normalise open conversations about these topics, with specific mention of the Dying Matters campaign.

“Having been involved in Dying Matters I am well aware of how important it is to normalise conversations around dying and death. A lot of progress has been made but there is still a lot to be done” – Man in his 60s whose wife died of cancer, England

The organisational evidence highlighted the importance and benefit of national public awareness campaigns. The Dying Matters campaign was praised for recognising the need to deliberately and proactively diversify the groups of people that have a platform, so that a wider set of experiences are heard, elevated and understood - including men and younger people. Videos developed by BrumYODO the British Islamic Medical Association for the Muslim British Asian community on death, dying and bereavement in the context of the pandemic were also signposted.

“We were just acutely aware that actually end-of-life hasn’t necessarily been discussed openly within the community, partly because, as an immigrant community, as a lot of Muslim communities are in the UK, there’s a bit of a disconnect from that tradition back home of death and dying. And now of my generation, second generation British Asian, we’re now seeing our elders go through the dying process, and obviously within the pandemic there’s been a lot of that. So for us it was quite key that we needed to help people of my generation really cope with or understand what death and dying might look like within the pandemic and to manage that. We developed videos which covered a plethora of topics related to the issue, but one of them was bereavement, and we’ve had really good feedback on that video series. It was digital, it was easily accessible, three-minute short clips, but full of tips, and opened up conversations really.” – Oral evidence

Organisations also mentioned the successes of specific national awareness initiatives in raising the profile of bereavement in public consciousness, for example Dying Matters Awareness Week, the National Day of Reflection, the Good Grief Festival, National Grief Awareness Week, Children's Grief Awareness Week and Baby Loss Awareness week.

What helps: public awareness

- Death and grief cafes – to break the taboo around death and dying
- Informal community networks and activities such as coffee mornings and walking groups
- National awareness, public engagement and education initiatives

Dying Matters Campaign

Dying Matters is a campaign by the charity Hospice UK working to create an open culture in which we’re comfortable talking about death, dying and grief.

There is an annual Dying Matters Awareness Week that encourages all communities to get talking about dying

National Grief Awareness Week

National Grief Awareness Week, coordinated by the Good Grief Trust, aims to raise awareness of the impact of grief and to create a unified voice for all bereavement services. The Week runs in early December, promoting simple messages that can help everyone support bereaved family and friends better

Barriers to support from communities

Experiences of isolation

A large number of respondents of all ages reported feeling **very isolated** following a bereavement.

“I don’t know how support could have been improved, I just know there was no support” -Woman in her 60s whose mother died following a stroke (England)

“I have never felt so abandoned. I have been left to try and live”. – Woman in her 60s whose husband died (England)

The lockdown restrictions which prevented families, friends and communities from supporting each other in traditional ways were very difficult for many respondents, as explored further below. While schools were closed, children were also unable to connect with their usual peer networks.

“Losing my grandfather, four months after losing my other grandfather in a traumatic way, whilst being isolated from my entire family was deeply troubling to me. I was unable to see my entire family for months afterwards. I was unable to attend the funeral - the only member of the close family who was unable to attend, everyone else was there. The lockdown rules at this time were incredibly strict and we were all unsure as to what we were able to do and despite me being in desperate need of care, support and assistance I was floating and lost without help”- Woman aged 18-30 whose grandfather died of cancer (Wales)

“Most bereaved people do not require specialist bereavement support if they receive a supportive response from existing networks such as schools, family, friends, communities and employers etc. The availability and accessibility of these networks is key, and the pandemic is likely to have had a detrimental impact on this as bereaved people may have had reduced access due to lockdowns/coronavirus restrictions”. (Children’s bereavement support organisation).

Many children and young people also reported feeling as though they were the only ones experiencing bereavement. Some children and young people reported that no-one had helped them, or that people didn’t understand what they were experiencing.

“Just horrible and feel a little alone” (13-15 year old)

“No one did [help]” (13-15 year old)

“People invalidating young peoples trauma and upset does not help, it leaves us feeling isolated and wrong for having big emotions” (16/17 year old)

A number of factors, in addition to those related to the pandemic, contributed to the sense of isolation that people of all ages experienced following a bereavement. The next section of the report explores some of the contributing factors.

Not wanting to burden others

For many respondents, there was a desire not to burden loved ones with their own emotions and experiences following a bereavement. This seemed to be a particular concern in relation to the pandemic, and the multiple deaths that many families, friendship groups and communities had experienced. This exacerbated the feelings of isolation described by many and acted as a barrier to receiving emotional support.

“Minimal support from family and friends - think everybody was just 'deathed' out - all we hear on the news/media is about death - for me there was an element of 'you've been through worse' as my husband had died previously, without people realising the impact of losing somebody who was another close link to my husband - I know my daughters felt this acutely.” – Woman in her 40s whose father in law died of COVID-19 (Scotland)

“Unable to share what was going on in my head.. with family. or friends they surely must of been suffering also” - man in his 50s whose wife died of cancer (Scotland)

“To be honest, I didn't feel I could talk as openly as I would have wanted to - concerned more about the needs of more vulnerable family members”. Woman in her 40s whose aunt, mother-in-law and father-in-law all died (England)

“
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”

The organisations who gave oral evidence identified feelings of embarrassment at needing and asking for help (seen at community bereavement help points), and the sense that others can't understand.

Some children and young people talked about how painful it was to see their families grieving. Children and their families sometimes tried to **protect each other** from their grief, which could leave them feeling even more isolated.

“Obviously it has affected family members a lot as well so it's not always that they have the energy to support someone else.” (16/17 year old)

“A common theme is that children are worried to share that with their parents in case they upset them and burden them.” (Children's bereavement support organisation)

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

A 13-15 YEAR OLD”

Demands of family life

As discussed in the previous chapter, many adult respondents described how coping with the tasks of everyday family life, in addition to the experience of bereavement was particularly challenging. This was a barrier to support from family and friends too. Children and young people also noted that bereavement may be an additional challenge for of already stressed families. Changes and arguments in the family could also get in the way of feeling supported.

“There should be legislation to protect those bereaved with kids. I would imagine a scheme similar to maternity leave. It's a huge shock to everyone. It's an impossible task sometimes with kids and all the paperwork.... plus the grief mixed in. I'm surprised I managed to survive” -Woman in her 40s whose husband died of cancer (England)

“I think the whole management of the estate piece needs to be looked at. I had two young children's grief to cope with on top of my own and the priority had to be the admin which was a massive task - why can't we find a simpler way to manage this? The admin impacted me immensely at a time when I really needed to stop and concentrate on my children and us as a family” – Woman in her 40s whose husband and father-in-law both died (England)

“There’s no time to grieve when you have bereaved children to support yourself. We are still suffering so much nearly five years on, nobody understands, nobody supports, it feels like nobody cares”. – Woman in her 40s whose husband died of cancer (England)

Discomfort talking about death and dying

A crucial issue underpinning the sense of isolation experienced by people of all ages was a societal avoidance or discomfort around talking about dying, death and bereavement. Adults described feeling misunderstood, avoided, and sometimes even ‘abandoned’ by friends and family in the months and years after their bereavement. There was a perception that people were generally uncomfortable with conversations about death and dying, and for this reason respondents felt emotionally isolated.

“None, no one wants to talk about it, it’s a very lonely journey” – 40 year old Woman whose mother died of a brain aneurysm (Northern Ireland)

Taboos around grief also hindered children and young people’s access to support. Societal attitudes to death, dying and bereavement can mean that adults attempt to ‘protect’ children by not talking in a meaningful way, leaving children unprepared when they are bereaved.

“Many people do not know how to respond to death, as it is often seen as a taboo subject. People do not always know what to say or how to react when someone is bereaved. This can often cause the bereaved to feel misunderstood and very isolated, especially children.” (Children’s bereavement support organisation)

“So we need to have a more broad conversation about how as a society our culture and the way that we talk to children and try and protect them and to try to shelter them from things like this actually harms them for the future because they are inadequately prepared for when grief does happen and it will happen at some point in everyone’s life”. (Children’s bereavement support organisation)

Many organisational respondents agreed that stigma surrounding conversations around death, dying and bereavement was a big problem that prevented people from coming forward for formal or informal support, as well as making people more reluctant to do advance planning and communicating their wishes to family (see Chapter four on death administration).

Organisations voiced a perception that this stigma around death and dying results in people seeing bereavement experiences as a private matter and being reluctant to seek external support. Stigma can be reinforced by cultural or faith norms; may particularly affect older generations and men (although availability of appropriate support may be an issue too) and may be related to stigma around mental health more generally. Fewer than 1 in 5 adult respondents to the Commission’s call for evidence were male (only 11% identified as cisgender men, 0.2% as transgender men), despite it being open to all genders, perhaps in itself reflecting a higher level of discomfort around this topic among men.

While some organisations felt the pandemic had made people and organisations more willing to talk about death, others felt this had been short-lived and had already passed.

“Public attitudes to grief, bereavement, and support are still barriers which prevent people getting the help they need. Many people are not comfortable talking about bereavement and loss.” – organisational respondent

The taboo nature of death, dying and bereavement in UK society meant that respondents frequently described not being able to talk to their friends and wider family about their grief. Language and terminology can also be a barrier to people finding words that they feel comfortable expressing and talking about their grief. This manifested in different ways including not reaching out to the person after a bereavement, minimising or dismissing the emotional reactions that people were experiencing, and even physically avoiding the bereaved person (for example by crossing to the other side of the road).

“My parents are very uncomfortable talking about feelings and on the rare occasions we spoke in the first few months, if I mentioned I was feeling low, my mother would dismiss it as being down to the weather. I

haven't seen my parents for over 3 years now, as I can't trust my mother not to make hurtful comments. We always had a difficult relationship but this has just finished it off. My sisters try to be kind but they don't really understand what I'm going through.” – Woman in her 40s whose best friend died of liver disease (England)

“The conversation stops as soon as "grief" comes up - this is very unhealthy as it can make the grieving person feel like they need to "put on a happy face" and avoid discussing their grief so as to avoid making the non-bereaved person uncomfortable.”- Woman in her 30s whose partner died of an immune disorder (England)

“People crossing the road to avoid me, tilted heads, shrugs and ‘I don't know what to say’” – Woman in her 50s whose husband died of cancer (England)

Several bereaved children and young people also spoke about their peers avoiding them, whispering about them, or other negative, or even bullying, behaviour, that could contribute to a feeling of isolation. This ostracisation was echoed by services.

“Friends not playing with me any more”. Girl, 7 years old

“It can be different but not everyone has to hide away from you just because of your loss”. Boy, 12 years old

“People whispering around me”. Boy, 10 years old

“School life may become difficult for them to engage within if they feel shame about the loss, for example if the death was a suicide. These feelings can have an impact on social circles and could also have a real impact on their ability to engage with learning. Suicide may lead to those experiencing bereavement being bullied by other young people because of the nature of the death.” (Children's bereavement support organisation)

During the pandemic, differing social attitudes towards COVID-19 restrictions (with conspiracy theories and denial at the extreme end), could make bereaved people feel isolated and ignored. Discussions of the virus 'only' causing the deaths of older people and those with underlying conditions made people who were grieving the death of someone in these groups feel as though these deaths didn't matter. Conversely, people who were bereaved during the pandemic through causes other than COVID-19 could be made to feel by the unrelenting media coverage of the pandemic that their losses were less important because their loved ones had not died of the virus.

Particular stigma around certain types of deaths

Beyond the general taboo around death and dying, respondents described heightened stigma around certain types of deaths. It was highlighted that this stigma and taboo diminishes support in some of the saddest circumstances.

Individuals bereaved by **suicide** felt there was still a stigma around it which acted as a further barrier to receiving support from family, friends and communities. They felt the cause of death had contributed to people avoiding the topic, doing less to support their family and to celebrate the person's life, and in some cases those around them even suggested they were responsible for the death by questioning if there was more they could have done to prevent it.

“The stigma of suicide made it difficult for people to approach me. Friends didn't want to talk about my daughter.” – Woman in her 50s whose daughter died of suicide (England)

“[Friends and family] don't want to talk about it too much (way my husband died) as it is a bit of a stigma. Some family kept asking what more I could have done which was hard whilst others disliked my husband (because of the debt and other behaviours he did before his death)” – another Woman in her 50s whose husband died of suicide (England)

“Our son's school were somewhat embarrassed to be associated with a suicide. They didn't allow any named memorial items like a bench, didn't invite in any mental health charities to work with other kids, and provided no support to our son's sibling who started the school the next term”. – Woman in her 40s whose son died of suicide (England)

“There is still ongoing stigma surrounding death, particularly when someone has taken their own life, when the death may be due to drugs or alcohol use or when someone has mental ill-health.” – organisational respondent

Parents whose **child had died** also described a heightened taboo around the death. They felt particularly poorly understood, unrecognised by society, and generally unsupported.

“No one talks to the bereaved Mother - they don't know what to say, so instead they say nothing. Death of a child does not leave a name for the parents, we aren't widowed or orphaned, we are unspoken about. The pain is too vast for most people to even comprehend. So it's avoided. Just looks and fleeting glances of pity making the loss effect ripple out into your whole life. It takes certain types of people to be able to sit in someone else darkness with them. Death of a child is about as dark as it gets.” – Woman in her 40s whose son died of cancer (England)

“Similarly, some people don't understand what it is like to lose a son or daughter, especially if they don't have any children. It's not easy.” – Woman in her 70s whose sister died of cancer (England)

Adults bereaved by **pregnancy loss and stillbirth** felt that these types of deaths were similarly not understood, and there was not enough awareness about them, particularly given the number of people affected, or about how to support affected families.

“People need to be aware that baby loss happens and they should be shown how to help with the grieving process.” – Woman aged 18-30 whose daughter was stillborn (England)

“A lot of people don't understand that stillbirth is STILL BIRTH and parents have to go through the same process as every other labour but without the healthy child at the end of it. I had a lot of inconsiderate comments and still do mainly because people don't understand and there's no education about it because it's such a sad subject but it's even more important to educate about the sad subjects so that when people go through them they aren't isolated.” - Woman aged 18-30 whose son died of sepsis (England)

Those bereaved by **COVID-19** had encountered stigma around the cause of death. They described experiencing disrespect towards the deceased and avoidance, driven by fear and ignorance.

“None [no support] from the community. Felt like I was a leper” – Woman in her 60s whose husband died of COVID-19 (Scotland)

Not knowing how to support someone

Linked to our societal reluctance to talk about death and dying, and experiences of avoidance, respondents often described how they felt that their friends and families did not know what to say to them, or how to help them. Organisations also reflected that taboos around talking about death made people feel too scared to support others who were bereaved. This may particularly be the case when the death was traumatic or unexpected. Some suggested that the idea of grief as a mental health/ medical condition might make people feel less confident offering support.

“Some people just stared at me and ignored it when some acknowledgement may have been nice.” (Young person 16/17)

“I feel death should be talked about more in all communities. I found that people did not contact me. Maybe because of COVID-19, but I felt upset by this. I would have rung friends to ask how they were. I did not get this.” – Woman in her 70s whose husband died of cancer (England)

“In our experience individuals and organisations feel helpless and de-skilled in the area of bereavement and grief support. People are frightened and reticent about doing or saying the wrong thing so their response is often to do little and to remain silent” – organisational respondent

Some respondents were also sad or frustrated their friends and relatives failed to proactively acknowledge their grief or talking about the person who died.

“Most people never acknowledge that my baby ever existed. Some friends sent messages saying they hoped I was surrounded by loved ones, but no one was there.” – Woman aged 18-30 whose son and grandparent both died (England)

“My friends didn't know what to say and didn't ask me about it or check-in with me, instead I spoke to them and I found it hard, uncomfortable and awkward so I stopped.” - Woman aged 18-30 whose grandmother died of COVID-19 (England)

Other respondents felt that when people did make contact, they were upset by well meaning, but misjudged comments. Perceived shortcomings in the support people received often had lasting negative impacts on friendships.

“Friends avoided talking about the twins, preferring to ignore or say things like 'You're young, you can try again' making me feel like I failed if I need to try again, and as though my children didn't matter if they could be so easily replaced. These are not the sort of phrases you would say to someone who lost their partner” –Woman in her 30s whose twin daughters were stillborn (England)

“Some friends were exceptional and intuitively knew what to do, and others (even particularly close friends) got it very, very wrong which I found very surprising and hurtful. I didn't feel like I could (or should have to) explain to people how to communicate with a bereaved person as that uses up precious energy, but I found that I was hugely preoccupied by the people who didn't support me in the way I would've liked, rather than allowing myself to feel loved/supported from those who were there”– Woman in her 30s whose mother died of cancer (England)

Unhelpful attitudes and insensitivity can be upsetting. There was a feeling that people don't understand if they haven't been through it – particularly in the pandemic context.

“In our experience, many clients experience a lack of understanding around the process of grief and how long grieving may take. There is a sense that grieving is a linear process based around the stages of grief, and the expectation from society is that clients need to get on with it, then draw a line and get over their grief.” – organisational respondent

“We do not believe that the impact of the pandemic upon those who have lost family and friends is properly understood in a society rushing back to normality and in so doing crossing the road to avoid the grieving.” – organisational respondents

Children and young people themselves, and the organisations who worked with them, recognised that they may not have the language to express their grief and ask for support, and adults around them may not recognise or acknowledge it.

“The impact of grief is often misunderstood and underestimated, with some behaviours, particularly in children, not readily identified as grief-related”. (Children's bereavement support organisation)

“Children who are grieving are experiencing a potentially overwhelming range of feelings and emotions at a time when they may not have the language to express to it.” (Children's bereavement support organisation)

“Everyone sees it as me just misbehaving maybe if teachers and any other adults involved were trained to see the signs I wouldn't of been left for the last 18months with no support” (13-15 year old)

Particular groups can face difficulties in getting support from family, friends and the community, including children and young people in the care system where the person who died was not known to their carer.

Misconception that grief is time-bound

Respondents consistently felt there was a lack of understanding of the longevity of grief. They described an expectation and sense of pressure from people around them to 'get over' their grief and return to 'normal', and a failure from friends and family to appreciate that grief never goes away.

A dominant theme in the adult evidence was that initial support from friends and family ended too early. Friends and relatives who had initially provided emotional and practical support immediately after the death tended to 'go back to their normal lives' in the months or years after, when in some cases their support was most needed. It is clear that even those who do receive support from friends and family are rarely supported for long enough.

"Friends etc are there at the very beginning but then 'disappear' in the sense that they stop asking how you are. I think they forget that you're grieving and maybe don't understand that grief goes on as long as you live." – Woman in her 50s whose partner died of alcoholism (England)

"Friends have been very supportive in the first year after his bereavement; but less so as time has gone on". (Parent of 5-12 year old)

"Friends they didn't know what to say and after a bit of time passes it's as if they think it's gone, they never mention it again." – Woman aged 18-30 whose father died of a heart attack (England)

"Others have gone back to their normal lives and presumably think I've done the same - which will never be the case" – Woman in her 70s whose husband died of sepsis (Wales)

Community initiatives not available in all areas

The adult evidence revealed that access to informal community groups and bereavement cafes varied regionally. Several respondents who were aware of them expressed regret that they were unable to go to a grief café as there was not one in their area.

"I would have liked to attend a bereavement cafe, rather than one to one support but this was not available in my area." – Woman in her 60s whose husband died of a stroke and pneumonia, (England)

Impacts of the pandemic

74% of adults bereaved during the pandemic said they had experienced social isolation and loneliness after the death. Over a third (35%) of adults said they had experienced difficulties with limited contact with friends and family and grieving alone.

"Isolating people who didn't have COVID-19 from relatives was ridiculous and cruel and completely wrong." – Woman in her 60s whose two sisters and nephew died (England)

Social distancing had also had a significant impact on the way in which families and friends were able to come together to support one another in grief as they would usually do. During lockdowns, families had been grieving together in intense circumstances, isolated from their wider support networks and without the usual outlets of school or work, which had put them under significant strain.

"Bereaved children and families have also struggled with increased isolation, prolonging the most difficult phases of grief." – Children's bereavement support organisation

“For many people not having the support of your family as they were not allowed to visit you due to COVID-19 regulations following a bereavement has been devastating. Mental health has been impacted negatively”. – Children’s bereavement support organisation

“It’s also been difficult for parents and carers, who are going through their own grief while also having their children at home 24/7.” – Children’s bereavement support organisation

31% of young people had been affected by periods of school or college closure. Being out of school had denied children and young people a usual routine and opportunity for support. By the time they returned to school, their bereavement might not be seen as ‘recent’ and was therefore less likely to result in support.

“School closures meant many children were denied an important source of routine, stability and support at a time when they needed it most.” – Children’s bereavement support organisation

Pressures had been particularly acute for children and families already in disadvantaged circumstances.

“For many families living in poverty this is a tough time as they struggle to home-school , often without the appropriate technology and in overcrowded living conditions . The stresses and strains cannot be underestimated.” – Children’s bereavement support organisation

The pandemic increased general levels of anxiety among people of all ages, including those who had been bereaved. Fear of catching or spreading COVID-19 also affected people’s ability to cope and go about their daily lives, and increased isolation, particularly amongst people bereaved by the virus. 27.2% of adults and 15% of children and young people said they experienced difficulties caused by fears of COVID-19. Individuals and organisations noted feelings of guilt about transmitting the virus.

Change needed improve support provided by family, friends and communities

A. Cultural change

Communities play a role in educating, raising awareness and giving people the language and tools to support each other when emotional support is needed after a bereavement. There is a need to increase death literacy and encourage people to share their experiences within their communities.

For this support to be in place, bereaved children, young people, parents, adults and organisations all spoke of the need for **public attitudes around death, dying and bereavement to shift** towards a more compassionate approach, where these topics are not taboo.

This means being aware of the different nuances within communities as to how they approach that discussion- the language and talking about death, dying and bereavement is critical. We need to normalise grief but need to recognise that this may need to be done in different ways for different communities.

There was a clear awareness that the pandemic has exposed a whole generation of children to death, dying and bereavement, and this presents society with an opportunity to change the conversation around this important topic. Organisations talked about the value of giving a bigger platform to national campaigning around bereavement mentioned at the beginning of this chapter and increased awareness raising across different media channels to reach all groups of society.

Bereavement-focused campaigns which can raise awareness, challenge taboos and break down barriers to talking about death and grief (Children's bereavement support organisation)

Increased awareness via all media channels help, seeing people they relate to talking about their grief and the support they have received (Children's bereavement support organisation)

"Campaigns and organisations such as Dying Matters and The Order of the Good Death need to have a bigger platform to encourage people to have conversations about what is an inevitable part of life" – Woman in her 40s whose husband died of liver disease, England

Respondents felt that important messages to convey included the normality of grief and reassurance that bereaved people are not alone; how different cultures and faiths grieve and how to support someone who is bereaved.

"I think people should talk about grieving much more. It's normal you know." (5-12 year old)

"A better understanding of other cultures and faiths and how they grieve could enable people to feel better understood, and ultimately supported. For example, in some faiths where death is seen as 'God's will', there can be challenges around people feeling able to express their feelings or ask for support." (children's bereavement support organisation)

"More training to know what to say and when to just listen and not be afraid" (16/17 year old)

Respondents to our survey shared some ideas of what good support from family and friends might look like. These included actively listening whenever an individual might want to talk about their bereavement without forcing a conversation, and creating a sense of safety.

"It's not hard - just checking in, not expecting a reply, and listening. We need to teach this in our society." Woman in her 40s whose sister died of cancer (England)

"Give them a feeling of safety" (13-15 year old)

"Talk to them but don't force them, be ready for whenever they feel comfortable. Don't cross boundaries and baby them but don't go overboard and suffocate them. Communicate with them about what they need" (13-15 year old)

Key suggestions for public awareness campaigns:

- Take a public health approach and avoid medicalising grief – recognising grief as a normal part of life and not presenting it as a pathological problem
- Normalise conversations about death, dying and bereavement and reduce the taboo, including the taboo and stigma around certain types of deaths such as suicide and child deaths
- Advocate talking about death and grief in advance of death/bereavement
- Raise awareness of how adults and children grieve
- Raise awareness of how to support bereaved adults and children, including what to say and what not to say to someone who is bereaved
- Give the public the language to engage in conversations, to create open environments for discussing grief and loss and accessible information about how to support someone
- Learn from mental health awareness campaigns such as Time to Talk
- Build on existing campaigns such as Dying Matters
- Help people to identify what is normal and abnormal grieving in themselves and others
- Raise awareness of specific types of bereavement such as baby loss, sudden loss and loss due to COVID-19
- Challenge current attitudes that grief is a time-bound experience with an 'end' - support needs to be offered over a long time period
- Reflect and meet the bereavement needs of diverse communities, cultures and religions including actively engaging with different communities through awareness of the nuances within communities as to how they approach discussions around death, dying and bereavement
- Use diverse public figures to give voice to different perspectives and experiences
- Highlight the available financial support if you are bereaved (this could be a separate or parallel public awareness campaign)
- Use art to help translate experiences across space and time
- Provide all of the above for different audiences, including
 - available in different languages, being mindful of the different cultural expectations around death, dying and bereavement
 - Black, Asian and ethnic minority communities
 - Children and young people
 - Those who are neurodivergent
 - Those who are homeless, or otherwise disenfranchised in society



B. Equipping communities to provide more support

Many individuals spoke positively about the Compassionate Communities Movement as a public health initiative that needs to be rolled out further. This approach needs funding and support to continue developing networks, and healthcare professionals and bereavement support providers need to be aware of the types of formal and informal support groups that exist in their areas, in order to signpost.

“Community hubs/initiatives would be a welcome way to go offering bereavement support in an informal setting, maybe a weekly meet up for coffee and a chat that might evolve into a lunch group, theatre group, walk and talk support group, maybe with more formal speakers from the bereavement sector to check in and support those needing more formal intervention and clinical support.” – Woman in her 60s whose mother died of a terminal illness, England

“Better access to bereavement peer support groups and bereavement cafes (eg The Good Grief Trust). More funding for these. More publicity about these.” – Woman in her 40s whose father died of a stroke, Wales

“Many more social groups. Grief cafes. Walking groups.” -Woman in her 60s whose husband died of cancer, England

Some organisations felt that lessons needed to be learned for the Government’s response to any future pandemic events. Suggestions included that restrictions on funeral attendance should only be made as a last resort, and that social restrictions should be developed acknowledging concerns of particular cultural and faith groups.

“Consideration of the need to balance mental health considerations with infection control when making decisions about social restrictions that affect bereaved people such as visiting inpatient units, funeral arrangements and enabling social support” - organisational respondent

C. Grief Education

Organisations and adults pointed out there is a chance to change or re-shape the narrative at a younger age before attitudes become inflexible. Individual respondents to the survey felt exposure to grief and dying in schools would help the next generation to understand these better and cope with grief in a more health way.

“Education and exposure of children to grief and dying at an early age in schools be it a pet or talk about feelings of losing a loved one will help the next generation”- Woman in her 50s whose mother-in-law died of a terminal illness, Wales

“I think education around ‘death and grief’ should begin in schools; we will all die however, as a nation, we generally do not talk about death and most do not know how to approach the topic, how to support one another, how to ask for help etc” – Woman in her 50s whose son died in an accident (England)

Many organisations agreed with the role schools could play in providing education on grief awareness and the practical side of planning for end of life. This would require investment and training for teachers – and local charities could be brought in to share expertise.

Some suggested **death education should be a mandatory part of the curriculum** – in the Health and Wellbeing area in the new Welsh schools curriculum, or as part of Relationships and Sex Education in England.

Organisations highlighted the **importance of looking forward** when thinking about grief education, and how we can positively influence the **next generation to offer understanding and compassion** to those who will be bereaved.

In addition to the children and young people’s call for evidence, the UK Commission also worked with Votes for Schools to find out what children and young people thought about loss and bereavement, specifically if this subject should be taught at educational settings. Over 31,000 children and young people took part in the vote, considering the following topics:

Primary topics

'Is loss too hard to talk about?'

'Should all children learn about coping with loss and bereavement at school?'

Secondary and College topic

'Should learning about coping with loss and bereavement be included on the curriculum?'

58% of primary school pupils, 38% of secondary school pupils and 65% of college students voted to have lessons on how to cope with loss and bereavement in school.

The students who voted 'yes' felt that this topic was important and needed to be taught, due to the understanding that **loss and bereavement is a universal experience** that everyone will be affected by at some point in their lives. Students who voted against this idea felt the topic was too sensitive to be discussed in school. Potential mitigations offered by those who voted 'yes' are outlined in the appendix.

"I think I will deal with bereavement when I have to but it would be good to have a range of strategies to choose from." – Secondary school response

"It was really good this topic because if you know how someone feels, you can help them." – Primary school response

"Everyone deals with loss so it is important that we know how to healthily cope with it without jeopardising our mental health in the long term." – Secondary school response

Outside the Votes for School responses, other children, young people, parents and organisations working with bereaved children agreed that **grief education was essential**. Grief education would help all children and young people to understand what happens when you are bereaved, to support others going through a bereavement and to support themselves if it happens to them. Grief education would be helpful to challenge unhelpful narratives, expectations and language around bereavement, both from peers and from staff.

"Eventually everyone is going to go through this so if they know how to cope or help people then it will be much easier." – Primary school response

This change should start in school where death is often already within the curriculum by accident but never discussed, one only has to look at primary schools all of whom teach fairy tales, most of which feature a dead parent, but this element is never opened for informed discussion. (Oral evidence session)

Students also noted that by learning about loss and bereavement, they would be more **prepared for the future**, by understanding that the **experiences and feelings you may have are normal**. Students were especially aware that learning about this topic would support them, with many pointing out that coping strategies would be welcome.

"We should talk about it as it is a reality in life and a skill we need to learn for life". – Primary school response

"I believe that is a big life skill to learn how to deal with grief, and losing a loved one can change someone's like forever." – Secondary school response

"As a Thrive school, many children felt it was healthy to talk about loss and bereavement and link our emotions and strategies to cope." – Primary school response

"I think I will deal with bereavement when I have to but it would be good to have a range of strategies to choose from." – Secondary school response

Others highlighted the importance of **understanding and supporting those peers and friends** who may be experiencing a bereavement during school life.

*"It was really good this topic because if you know how someone feels, you can help them." –
Primary school response*

"I think it was a great topic because it really touched peoples hearts and I think we can learn more about it since lots of people go through it and we can learn how to behave around people who are grieving." – Secondary school response

"Made us think of ways we can help each other, it can help maintain good friendships understanding each other." – Secondary school response

Some pupils made the connection that there will be **bereaved peers** who are dealing with this situation, and an awareness that it would **support pupil's mental health overall**.

"I think it is a great ideas because me being someone that lost someone close to me I find it quite hard to cope with my emotions and I keep it quite bubbled up and I don't tell anyone about how I'm feeling." – Primary school response

"I would say about 1 of 5 people in this school have had to deal with loss at some point in there lives, so whether they dealt with it alone or had someone to help them, it would help even just the slightest bit to have some support, other that the pastoral." – Secondary school response

"Everyone deals with loss so it is important that we know how to healthily cope with it without jeopardising our mental health in the long term." – Secondary school response

*"However, our feelings are valuable and important, and recognising them is worthwhile." –
Secondary school response*

One comment highlighted that loss and bereavement applies to **other forms of change (loss)** and this understanding could help to support students:

"It was an eye-opener to realise that some children may be angry about moving school, we should have a better understanding." - Primary school response

Conclusions and recommendations to overcome barriers to support from family, friends and communities

As we have seen, good support from family, friends and communities can play a critical role in providing comfort and connection through the isolating experience of grief and is very highly valued by those who receive it.

However, sadly, not everybody is supported by these key groups during a bereavement. As a society, we are overwhelmingly still not comfortable talking about death, dying and bereavement, or in supporting people who are grieving; which is why we are calling for the following changes to help to normalise conversations, increase understanding, 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, prioritising under-served and minoritised 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, 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 should be required to provide opportunities for children to learn about coping with death and bereavement as part of life.

In this chapter we have explored the role of, and barriers to, support from friends, relatives and local communities. In the next chapter, we will look at how bereaved people are supported in wider community settings - schools, colleges and workplaces.

2

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

“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

The previous chapter highlighted the need for a community approach to support. 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, crucially, these settings are also places where people have to work or study- to “perform”. Getting the support right through the emotional and practical challenges of a bereavement, is critical to ensuring individuals stay and thrive in employment and education. The stories that were shared with the commission illustrate the significant difference good support makes and the distress caused when it is lacking. Inadequate support in these settings risks contributing to poor outcomes in all areas from mental health to long-term employment and economic prospects.

Key findings:

- A third of adult respondents said they were not at all supported or only a little bit supported by their employer.
- Children and young people reported even less support from schools and colleges with half (49%) saying they were only a little not at all supported, and one third (34%) saying they were not at all supported

- In workplaces, there was variation in all aspects of support including: supportive cultures; paid leave; returning to work; longer term flexibility and adjustments; access to employee assistance programmes and access to workplace bereavement networks
- In education settings parents and students described variation in all aspects of support including: communication and information sharing; adjustments and sensitivity to the bereavement over time and 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
- Suggestions for change identified by respondents included:
 - Bereavement policies in education settings and workplaces
 - Staff training in bereavement
 - Supportive and compassionate cultures in these settings

The first part of this chapter explores experiences of support in workplaces; the second section experiences in education settings; the third section identifies barriers to support across all these settings; and the final section outlines change needed and the Commission's key recommendations.

Workplaces

Survey respondents who were employees were asked to rate how supportive their employer had been during their bereavement on a four-point scale from “not at all supported (1)” to “very well supported (4).”

A third of adult respondents said they were not at all supported or only a little bit supported by their employer. Support from employers was given a mean rating⁶ of “a little bit supported”.

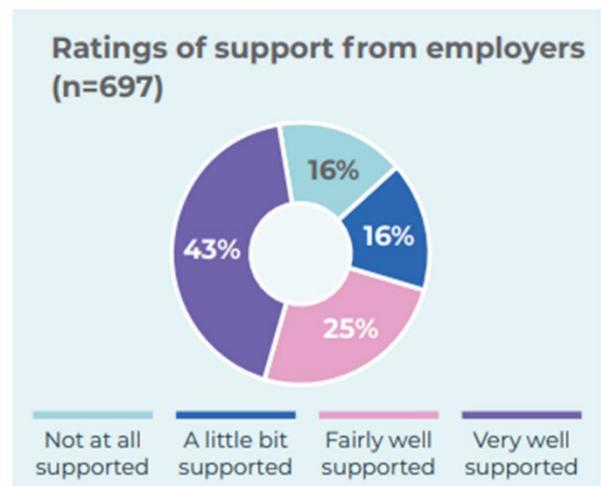
Although the most-selected option indicated the highest level of support, still over 50% of adults felt further support could have been offered by their employer.

For young workers, the question was only relevant to two people, and they said their employers did not support them ‘at all,’ or only supported them ‘a little bit.’

Variation in employee experiences

People shared a wide range of experiences of employer support after a bereavement. While two in five respondents reported that they were very well supported, around one in three said that they received no or minimal support from their employer during their bereavement. Much more needs to be done to ensure all employees receive the support they need from their workplace following a bereavement.

The subsections below provide details about what good support looked like, as well as showing what situations with poor support or a total lack of support looked and felt like for people who were employed when they were bereaved.



Note. The chart represents responses from 697 adults.

The section covers various forms of support such as paid leave, organisational culture and flexibility upon return to work and gives examples of how these forms of support, or the lack thereof, can impact people who are employed and bereaved.

A. Supportive cultures within organisations

Many examples were provided in which people felt well supported by their employers. Respondents described how in some organisations there was a supportive culture, with people feeling that they were treated with compassion and respect. Respondents spoke positively of employers who were sensitive, understanding, and accommodating of their needs, both practical and emotional. In cases where the death was expected, this included flexibility and support both before and after the death.

*“Work colleagues being open to accepting me, my grief, and being willing to speak about my loss”
- Woman in her 40s whose father died (cause not disclosed), (Scotland)*

“My boss called me and said she didn’t expect me to think about work, take the time I needed, allowed me to stay with my mum (who lives 360 miles away) as long as I needed. This allowed me to grieve myself, to support her practically and arrange the funeral. My colleagues supported by picking up my work and also kept in touch.”- Woman in her 30s whose father died of sepsis (England)

⁶ $M = 2.95, SD = 1.13$

The oral evidence highlighted a helpful project by Dying Matters called “Compassionate Employers” which focusses on creating positive workplace cultures to support bereaved employees.

“I think that the risk from an employment perspective is that employers and companies think, We’ve got a bereavement policy. It’s written on a piece of paper, and it’s saved on a share drive somewhere. But actually while that is critically important to get right, it’s about creating a culture at a work place in which people feel safe and comfortable.” – organisation respondent in the oral evidence

However, these positive experiences of support were not universal. Other respondents described experiencing an absence of support from their employers. They described how their managers were not comfortable talking to them about their loss and organisations varied in their policies around communicating deaths to other colleagues.

“Acknowledging me and the death of my husband would have been a start. But they didn’t even do that. No contact from them. Nothing. Just “when are you coming back to work” - Woman in her 30s, whose husband died of alcoholism, (England)

“I didn’t get offered any support from my bosses. Out of sight out of mind” - Woman in her 60s whose mother died of a stroke (England)

“Expectations, I felt my employer expected too much from me too soon. I felt there was a lack of understanding that a suicide is a complicated death and the grief around that is complicated and hard to cope with and I was grieving in a pandemic. There was a mixed message from my boss and HR that it was ok to not be ok but then only up to a point.” - Woman in her 40s, whose husband died of suicide, (England)

In the oral evidence, witnesses described perceived insensitivity and a lack of understanding and compassion amongst managers and colleagues, reluctance to take leave from work as people worried about losing their jobs or livelihoods. Others described the isolating effects of being furloughed or working remotely; making it harder for them to connect with and feel supported by their colleagues.

What Helps

- The Chartered Institute of Personnel and Development and Business in the Community have both produced guidance for employers on developing a compassionate bereavement policy.
- Marie Curie has guidance for bereaved employees and for their managers on supporting bereaved employees, including how to develop a bereavement policy.

B. Paid leave

There was variation in the amount of time off, and paid time off, offered following a bereavement. It was clear that across and even within organisations, there were often not clear policies about bereavement leave, who was entitled to it and how long they could be away from work. This left people feeling unsure about the amount of time that they could take off, which created extra pressures.

“The work policy on time off was vague and my efforts to get it improved proved fruitless. A colleague also suggested a holiday would help me “get over it”.” - Woman in her 40s, whose father died (cause not disclosed) (England)

“I didn’t know what was a fair amount of time to take and would have helped if I’d been given a parameter to work too. I returned to work rather than taking more time off” -Woman in her 40s, whose friend and uncle both died (Wales)

Paid time away from work was a key aspect of support from employers, both before the death of the person they were close to and afterwards. Many respondents described how it would not have been possible to deal with both the practical and emotional issues surrounding bereavement and work simultaneously, and their employers had adjusted their policies accordingly.

“Allowed carers’ leave when required and allowed compassionate leave after death. Recognised when I was struggling after her death and encouraged me to take time off sick to grieve and focus on my own wellbeing”. - Woman aged 18-30, whose grandparent died of COVID-19 (England)

“I was allowed time away from work to provide care once a terminal diagnosis had been made; this was very important to both of us so we could spend time together. They regularly checked how we were and kept my job open” - Woman in her 60s whose husband died of cancer, (England)

“My employer extended my bereavement leave from 3 days to 1 month. If my employer chose to adhere to 3 days of bereavement leave, I would not be able to sort out all the financial affairs and childcare in 3 days.” - Woman in her 30s whose partner died of complications from a heart condition (Northern Ireland)

In contrast, several respondents described not receiving adequate paid time off following the death of their loved one. Many respondents felt pressured to return to work for fear of losing their jobs, or because leave that was given was not paid. Many respondents described having to take annual leave to attend funerals or to deal with administrative tasks associated with bereavement.

“I was only given five days ‘compassionate’ leave from work so took another five days unpaid, which meant I had to borrow money to pay my bills the following month” - Woman in her 50s whose daughter and father both died (England)

“Maximum of 5 days special leave was allowed to deal with all aspects of the death - starting from day of death. Clearly whoever set that rule had never been through the process themselves. I had to take annual leave to attend my husband’s funeral.” – Woman in her 60s whose husband died of acute pancreatitis (England)

Insufficient bereavement leave can mean that for some people taking sick leave is their only option. Minimal time off was a particular challenge for people employed on zero hours contracts, the self-employed and people that had only recently joined an organization when they experienced a bereavement.

“I was working for an employer on a zero hours contract, so to take time off to grieve my Mum and attend her funeral I wasn’t paid at all. My Dad had to help my partner and I cover our rent at a time when he was also stricken with grief because I couldn’t get any financial support (not entitled to benefits as I was technically still in work and my employer didn’t offer me any paid compassionate leave whatsoever.)” – Woman in her 40s whose mother died of a terminal illness (England)

“I ended up taking 3 months sick leave some months later as I was not emotionally coping well [after insufficient bereavement leave].” - Woman in her 30s who had a miscarriage (England)

C. Flexibility around returning to work

There was variation in the type and amount of contact that respondents had with their employers while they were on leave following a bereavement. Employers keeping in touch, but not applying pressure to return to work was valued by those that received this type of support.

“And they checked in on me to make sure I was okay and not under any pressure to go back until ready”- Woman in her 30s whose mother died of cancer (England)

While some respondents felt that their employers gave them enough time off to process their loss and to come to terms with their new normal, others described feeling pressured to return to work often sooner than they would have preferred.

“After the funeral kept asking when am I coming back? So felt I had to go back probably at a time I wasn’t ready. Was supposed to be phased return but wasn’t. When I returned a few thought I

had been on holiday that was quite hard to hear.” – Woman in her 40s whose father died of cancer (Northern Ireland)

“I wasn't sure what I was entitled to leave wise, didn't want to add to the team workload by being off for too long” – Woman in her 30s whose grandparent died of COVID-19 (England)

For those that received good support from their employers, several things around returning to work were identified as helpful. Taking a phased return to work, being enabled to work flexibly, in a different location or with reduced working hours were all characteristics of good support that individuals received from their employers:

“My employer allowed me to take time off work, and supported my phased return to work over the following 6 months without decreasing my pay. Subsequently they allowed me to reduce my hours and work flexibly” – Woman in her 40s whose husband/partner died of cancer (England)

“Flexibility, understanding, additional leave days, good communication, understanding that my hours needed to change, understanding that dates would be difficult ongoing” - Woman in her 50s whose husband died of cancer (England)

In contrast, others felt that managers did not allow them sufficient time or space following a bereavement, or that they did not take into account the longer-term impact of the bereavement on their wellbeing or performance.

“Bullying from manager directly after the 5 days' compassionate leave to complete a significant piece of work. He did not understand the traumatic experience I had been through or that I had to sort out a funeral alone. He didn't care at all.” – Woman in her 40s whose father died of COVID-19 (England)

Furthermore, some employers did not delegate the bereaved persons' workload in their absence meaning they returned to a backlog of incomplete work which added to the stress and pressure they experienced.

“I returned to work 6 weeks after losing my husband, this was before I even returned home because I was worried that they would not continue to pay me and I would risk losing my job. In the 6 weeks I was away no one had picked up any of my work and I struggled work as effectively. I have finally caught up 6 months and a lot of extra hours later.” – Woman in her 40s whose husband died of suicide (England)

Some employers recognised that the impact of a bereavement would likely be long term, both in relation to the respondent's ability to function at work and also in terms of their emotional wellbeing and made adjustments to accommodate potential fluctuations in both.

“They have recognised that support would be needed for some time after the initial event and continue to make accommodations as required” – Woman in her 40s whose husband died of terminal illness (England)

“I was allowed time off fully paid and also given a safe space to hide when I got emotional or if things got too much during work hours.” – Woman in her 40s whose husband died in a road traffic collision (England)

For those that did not feel supported, recognition of the long-term impact of bereavement was often missing.

“Expectation that following the bereavement, work and life should just resume as if nothing had happened.” – Woman in her 40s whose mother died of cancer (England)

Several respondents described the impact of the lack of adjustments or understanding made by their employers on their physical and mental wellbeing after returning to work. For some, this impacted their mental health or resulted in people ending their careers early. In the oral evidence, people in frontline jobs also described difficulties managing their grief and working in pressured public-facing roles.

“Didn’t support me in returning to work, was expected to go back full time and manage a large team with no help. I ended up being signed off for a month by the GP - which my company were angry rather than supportive about. On my return they just piled on the pressure, and there was zero understanding of the physical side effects of grief.” – Woman in her 30s whose mother died of sepsis and pancreatic cancer (England)

“Recognise that grief does not resolve within 2 weeks, and that individuals experiences differ. I returned to my job 2 months after my partner's death. It was only in the coming months that the reality of my bereavement was starting to sink in. Despite being open with my employer, I do not feel that they appreciated that grief affects your concentration. This resulted in performance management policies being put in place. The decline in my mental health (depression and anxiety) was exacerbated by this, and I felt hounded by my employers when I was signed off sick and given medication (that I'm still on, 18 months later), despite occupational health stating that I was not in a position to take part in any work related meetings. I felt that I had no option but to resign, from my 20 + year career.” – Woman in her 40s whose husband died of pneumonia (England)

D. Access to formal support through employers

Some individuals benefitted from referrals to employee assistance programmes which facilitated access to counselling and occupational therapy assessments.

“Employer arranged 6 sessions of therapy an gave me the opportunity to take extra time off whenever I was struggling with my grief...I originally contacted GP and was not given any support. Was told it was normal to feel like this. My work organised counselling which I am still receiving, it is helping, but it probably would have helped faster if it had been organised straight by GP when I originally requested it” – Woman in her 30s whose mother died of cancer (Wales)

The oral evidence highlighted the Workforce Wellbeing network in Northern Ireland, with an online hub of resources, set up to support the wellbeing of Health and Social Care staff during the COVID-19 pandemic and beyond.

E. Workplace bereavement networks

Organisations that recognised the impact of bereavement, and the potential role for peer support were viewed favourably by respondents. In particular the establishment and maintenance of bereavement networks at work were well received by respondents.

“I accessed a bereavement network when I returned to work which was one of the things that helped me the most as I could talk to other people who really understood” – Woman in her 50s whose husband died of cancer (Wales)

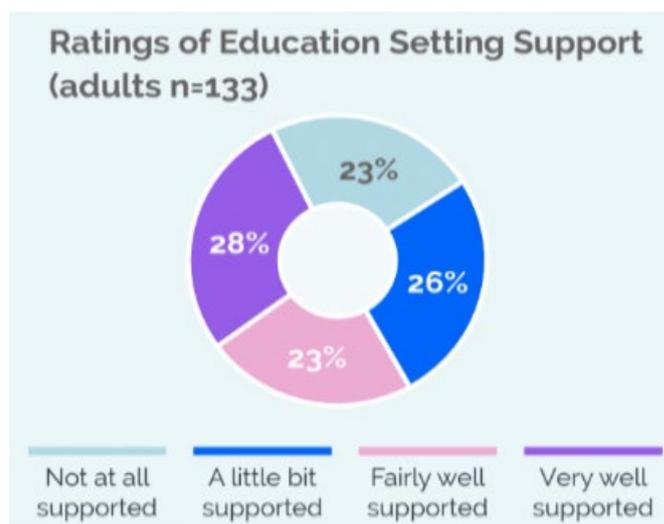
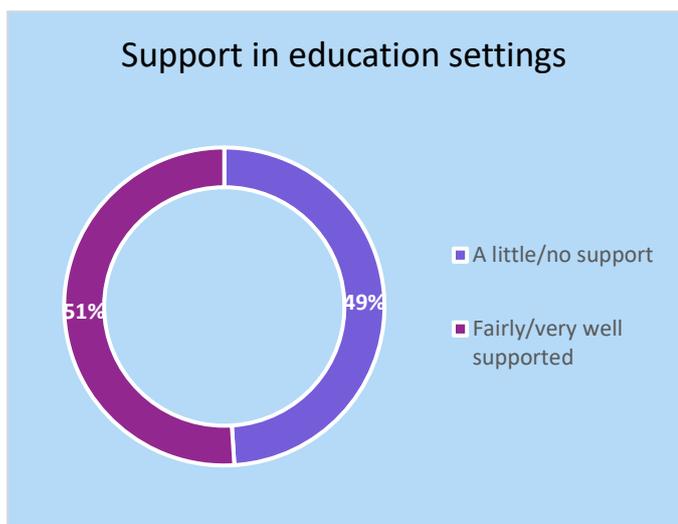
“I have helped start a grief and bereavement working party to improve support at work including policy, training and a fortnightly grief cafe - the growing attendance and sharing at this shows how valued it is, including by those who did not think they really needed support but turned up and realised they benefitted from the support (having locked grief away and not had anywhere to share it). The grief cafe is a safe space to share.” – Woman in her 50s whose husband died of a heart attack (England)

Educational settings: early years, schools and colleges

As the key place outside the family where children and young people spend so much of their time, schools and early years settings are a crucial element in the network of support available to bereaved children, young people and their parents and carers. The evidence the commission received highlighted parallels between schools and workplaces - both are settings in which bereaved people are expected to function and perform within a system or community.

Half of all children, young people and adults in education settings we heard from (49%) said they were not at all/only a little supported by their education setting.

Among the children and young people we heard from one third (34%) said they were not at all supported, and nearly half of those (45%) aged 13-15 received no support.



All adults, children and young people in education settings (198)

On average, 5–12-year-olds reported that they felt just below ‘fairly well supported’, while young people aged 16/17 reported they felt just above ‘a little bit supported’.

It should be noted that these answers reflect the experiences of those who participated in the research, but that it is not a populationally representative sample so shouldn’t be taken as representing the experience of everyone in education settings. The commission’s call for evidence aimed for depth rather than breadth of understanding school support and the rest of this section will provide quotes and qualitative evidence to provide context and understanding of how support provided to bereaved adults, young people and children is experienced.

	Adults	Children aged 5-12	Young people aged 13-15	Young people aged 16/17
Not at all supported	23% (n = 30)	14% (n = 3)	45% (n = 15)	33% (n = 4)
A little bit supported	26% (n = 35)	30% (n = 2)	15% (n = 5)	25% (n = 3)
Fairly well supported	23% (n = 30)	48% (n = 10)	30% (n = 9)	25% (n = 3)
Very well supported	28% (n = 38)	5% (n = 6)	9% (n = 3)	17% (n = 2)
Total number of responses	133	21	32	12

What helped in education settings

A. Supportive cultures

Many children, young people adults, and parents identified ways in which their school, university or early years setting had helped them in their bereavement. Parents mentioned these settings signposted to support and had provided financial support including flexibility with payments. Students mentioned flexibility around timing of coursework.

“My son’s nursery were amazing and gave me links to organisations to help my (then) 3 year old son, we’re flexible with payment for nursery and bought resources for my son.” (Parent)

“School is that contact outside of the home for a child and it’s so important that they feel supported in school because they are there so much of their time”. (Children’s bereavement support organisation)

For some children and young people, school can give them some respite from the grief and turmoil that may be happening at home when someone is dying or has died. When they felt well supported, being back in school was helpful for children and young people, although this needed to be at their pace – some felt pressured to attend before they were ready.

“I think a lot of kids in particular that sort of barrier where school is supposed to be the respite and as soon as they go home they come to this chaos and grief. So it can be so difficult to manage so they do need to have safe spaces where they feel they can retreat to” (Children’s bereavement support organisation)

B. Good communication in education settings

Echoing evidence on support from employers, communication was felt to be key in education settings. Parents spoke about the value of schools reaching out to acknowledge the death and put a plan in place for support and had appreciated this during closure periods too. This helped establish good communication between the school and home, informing many of the practical strategies that schools were able to put in place. Students valued communication around the death too and spoke of the value of having someone to talk to.

C. An identified key contact in education settings

Reflecting the benefit of good communication, respondents shared that having an identified key person or main contact helped, both around the immediate return to school, and over time.

Echoing views of support from employers, the most frequently mentioned aspect of help in school was having someone to talk to. In many cases this was a school counsellor but other roles were mentioned including class teachers, head teacher and **Emotional literacy support** assistants (ELSAs)). Sometimes this was to specifically talk about their feelings around the death and bereavement, but less formal talk was also valued.

“I regularly saw the school counsellor” (13-15 year old)

“There is also someone I can talk to who makes me a cup of tea and we can chat, and she goes when I need or want some alone time” (16/17 year old)

“Her form teacher kept an eye out for her & was available if she needed to talk about things” (Parent of 5-12 year old)

“We have parents that are feeding back saying they have been reached out by a member of the school who has come to the funeral and who has been that main contact for the child, that there has been much more of a softer approach around the child.” (Children’s bereavement support organisation)”

D. A plan for adjustments in education settings

Also echoing the evidence on workplace flexibility and adjustments, organisations and individuals spoke of the value of having a clear plan in place for adjustments in education settings over time. Examples included: allowing time out of class within the school day when feeling overwhelmed, including when the topic of a lesson was painful; planning for difficult dates, such as Mother’s Day, Father’s Day and death anniversaries, with leeway on lateness and absence on these occasions; allowing specialist support during school hours; and making adjustments such as extra time to complete work. This would ensure both that challenging situations were anticipated early, and that support was conscious of the longevity of grief.

“The new school have been fantastic offering help, respecting certain dates are hard and having plans in place before them dates come across.” (Parent of 5-12 year old)

“At school, my teachers gave me extra time to do work so I was less stressed.” (13-15 year old)

My university were excellent and got the links to the referral forms for essays due so I could complete and send back easily.” – Woman in 30s whose father died of a terminal illness (England)

Parents and organisations also spoke of the importance of careful management of information including informing relevant staff so there is a consistent approach, and letting the rest of the class know and sensitivity when corresponding with home e.g. around who invitations are addressed to.

“They also made sure that her class mates knew what had happened.” (Parent of 5-12 year old)

“We encourage all the schools we work with to develop a grief plan. The mere creation of this document often changes people’s views on how they should be reaching when a child/ member of staff experiences a bereavement.” (Child bereavement support organisation)

E. Links to formal support in education settings

Several parents were appreciative that their child’s school had **accessed training or worked in partnership** with their local child bereavement organisation to help inform the support they provided Organisations noted an improvement in schools’ willingness to engage with bereavement and to access training, partly since the pandemic.

“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 (England)

“Training is not about turning teachers into counsellors but equipping them to engender a bereavement-aware culture in the school environment (where children spend a significant proportion of their time) and a whole-school approach” (Child bereavement support organisation)

Not everyone received this support in education settings

Some students and their parents who shared their views with the commission reported disappointment and frustration with their school or college’s response to the bereavement. Organisations described the huge impact that this could have on children and young people’s grief.

“My daughter’s school ignored our situation and did not follow their grief policy. I have had to fight hard to get support for her”. (Parent)

Some reported that **no-one had acknowledged their bereavement** or the impact it was having on them. This left children them feeling isolated, with no-one to talk to.

“I knew my teachers all knew, but no-one spoke to me about the fact they knew, so it felt like an unspoken secret.” (13-15 year old)

“It unfortunately is still true for children that they experience the most painful most difficult thing they have ever gone through in their lives in one part of their world and then they turn up at school the next day, nobody says anything at all to the. We do still hear that”. (Children’s bereavement support organisation).

Several children and young people found that their experiences were **forgotten over time** – particularly as they moved into the next school year - and that to get further support they had to repeatedly explain the situation.

“I found after a few weeks going back to school my teachers started to forget, it’s been just over a year that I’ve lost my sister but I feel like sometimes the school forgets, it would be nice for them to still support me even if it was more than a year ago, grief is not a linear process and it can still be very hard!” (16/17 year old)

“The initial support was excellent. But one year on it has completely gone. But she is only just coming to terms with it.” (Parent of 5-12 year old)

For some, expectations of performance and attendance (from others or themselves) meant they felt under unhelpful pressure and others reported being disciplined for behaviours that they linked to their bereavement, and there were reports of children being sanctioned or excluded despite their circumstances.

“My school making me go to school when I just wanted to be with my mummy on my daddy’s birthday” (5-12 year old)

“I felt guilt when I asked for more time or help on work as I had already been getting help for I while”. (13-15 year old)

“My school telling mummy I was the naughty kid because I couldn’t sit still and concentrate.” (5-12 year old)

“My college was inflexible on their rule for never missing a session. I missed one evening seminar due to attending father’s funeral that day out of London and had to pay for and attend a whole make up weekend which felt unfair, disproportionate and unnecessary”. – man aged 18-30 whose father died of liver disease (England)

“Despite advice to schools not to exclude children without taking circumstances into account, young people [we] support are still occasionally being excluded for difficult behaviour following a bereavement”. (Children’s bereavement support organisation).

School closures during the pandemic meant a lack of structure and support for bereaved pupils. This also slowed referrals to specialist child bereavement services.

Barriers to support across work and education

Lack of awareness and confidence

Just as respondents found low awareness of grief to inhibit support from families, friends and communities, they equally identified it as an underpinning barrier in workplaces and education settings.

In education settings, while staff are often very keen to help, and have skills to understand children’s developmental needs and how to communicate with them appropriately, they can lack confidence specifically in using these skills in situations of bereavement. This can manifest as worrying about what to say, so saying nothing. This had been heightened during the pandemic, when children had heard more about death than usual, returning to school with questions which left teachers feeling under-skilled and unprepared.

“At a time when the support from trusted and familiar adults is needed the most, pupils can miss out because of uncertainty, anxiety and a lack of bereavement training among education professionals.” (Children’s bereavement support organisation)

Children, young people, parents and organisations pointed out how **certain behaviours warranted support** or attention, while others didn’t. Those whose grief wasn’t troublesome to those around them risked being ignored or forgotten.

“I didn’t sit in school and cry everyday and maybe that made them believe I wasn’t upset but no one not even my head of year has bothered to ask how i’m coping even as im in my last year of school and doing A levels” (16/17 year old)

“Anger gets attention (in the wrong way) and those who withdraw often are not offered support in school as they are not causing a problem with their behaviour.” (Child bereavement support organisation)

Similarly, in work settings, survey respondents identified poor understanding of grief, including specific types of bereavements and how to support someone, as a strong underpinning barrier to adequate support. Staff were simply not aware of either the emotional or practical challenges of grief or how to have sensitive conversations with students and employees. As with friends and families, some staff unhelpfully ignored the topic altogether, and others made insensitive comments or had unfair expectations.

“I felt there was a lack of understanding that a suicide is a complicated death and the grief around that is complicated and hard to cope with and I was grieving in a pandemic” - Woman in her 40s, whose husband died of suicide (England)

Inflexible systems

Wider school and employer settings can also thwart staffs’ wish to help, meaning they don’t have the permission to offer the support they want to.

“They understand why they need to help and they want to, but they don’t always feel they have the skills or the confidence and they sometimes feel that the system isn’t in their favour in the sense that they don’t always feel that they have permission to do that work to help” (Children’s bereavement support organisation).

Poor communication and management of information

Support for children and young people was also hampered by **poor communication and management of information** between staff and over time. This was felt to be more of a problem in secondary schools, where pupils were in contact with a greater number of staff. Organisations also pointed out how information could get lost over time, leading to children’s needs being overlooked.

“My children were offered no support by their schools. My daughter’s school did not tell people her Dad had died so as a 9 year old she was asked daily if her Dad was better. He had been dead a week before I found this out” (Parent)

“It is also hard for schools to identify the longer term needs of children who have been bereaved when they are not always aware of children’s backgrounds”. (Children’s bereavement support organisation).

In workplaces, it could be very painful for employees when they had not been consulted on the information sharing with other members of staff. For example, one woman spoke of how this had led to other colleagues presuming she had been on holiday while on bereavement leave.

“When I returned a few thought I had been on holiday that was quite hard to hear.” – Woman in her 40s whose father died of cancer (Northern Ireland)

Change needed in work and education settings

A wide range of suggestions were made across the evidence for improving support in education settings and workplaces, broadly across the areas of bereavement policies, staff training and wider cultural change.

A. Bereavement policies

Bereavement policies were a key recommendation in relation to both education and employment settings.

In workplaces

A number of organisational and adult respondents suggested that all employers (or all large employers) should have a **staff bereavement policy** in place to provide support.

“It would be good if all workplaces had a policy of bereavement support, no matter how big or small they are.” - Woman in her 60s, whose husband died of a terminal illness (Wales)

“It would be good if all workplaces had a policy of bereavement support, no matter how big or small they are.” A woman in her 60s, whose husband died of a terminal illness (Wales)

Suggestions for bereavement policies:

- Clearly communicated with transparency on paid leave
- Enable employers to take a flexible and ongoing approach to supporting grief, organisational that it isn't a linear process – including offering time off/ check ins on anniversaries, offering changes in role if required.
- Prompting managers to work in partnership with the grieving employee to establish what they want communicated, to whom, when and how; to be proactive in looking out for them and reaching out; reassuring about how workload will be managed in the near term
- Noticing changes and adjustments in behaviour and offering support accordingly; and being mindful of those working remotely
- Include a specific policy around pregnancy loss
- Employers should seek and implement feedback about what support people find helpful
- Recognise different cultural needs relating to mourning practices e.g. Nine Nights amongst the Caribbean Community

“Human resource departments need to be trained in dealing with cultural awareness when it comes to bereavement and that sort of thing, that is an important part that needs to be addressed.” -oral evidence

“Cultural differences on how certain cultures grieve will be very different because some of their grief process may not be within the first two weeks or something. For example, myself I had to do a religious ceremony every month, for the first 12 months. My workplace know about it, they knew certain days I will be two hours late for my work”- oral evidence

“We have aunties and uncles, they're not blood relatives but they are equally as important to us as our parents. My uncle died recently; he was my father's best friend at school. My uncle walked me down the aisle. He was Muslim, he died on a Thursday, he was buried on Friday morning.” - oral evidence

Survey respondents highlighted the value of Employee Assistance Programmes where they are in place. Some suggested that a template policy could be produced and circulated to employers, while others suggested that 'bereavement friendly workplaces' similar to 'carer friendly workplaces' should be introduced

Policies for frontline, health and social care staff

Respondents in the organisational and oral evidence highlighted the need for policies in healthcare and care home settings to address staff burnout relating to both workload and the 'moral injury' of high levels of bereavement from patients, residents and colleagues at all times, but especially following their experience of the pandemic.

The evidence also emphasized the added pressures and strains on bereavement volunteers and therapists, and lack of support from colleagues when working remotely, both during and beyond the pandemic.

“Workplaces should have their own policies to support staff after a bereavement - I work in the NHS and returned to work at the hospital where my husband died. After working there for 22 years I returned to no phone/desk/disabled email account/the loss of all my previous computer files. It made integrating back into my role very challenging at a time when I was most vulnerable.” – Woman in her 40s whose husband died of vasculitis (England)

Bereavement policies in schools

In addition to workplace policies, respondents suggested schools should have a bereavement policy in place – along with one for supporting those affected by a diagnosis of terminal illness – and staff trained to provide support to children who had been bereaved. A bereavement lead in each school and setting up children's peer support groups were also suggested.

Some organisations suggested this should be linked to the wider wellbeing agenda and to other relevant policies including safeguarding, behaviour and attendance. Respondents felt the process of developing a policy could help to shift thinking about how to support bereaved children.

“That involves policies in all schools but more recently they have adapted that to make sure that young people themselves actually drive the response the school makes. They put the young person at the centre of the discussion about what kind of support the young person wants to receive and who else needs to know. I think that kind of young person led model is really interesting and we know that agency is so critical for young people after something as critical in their life as grief and bereavement” (Children's bereavement support organisation)

Some organisational respondents felt that school and college approaches to bereavement should be more comprehensive, taking a whole setting approach, extending beyond the classroom, to ensure children and their families are fully supported.

“Maybe is it more around the support that the school can offer the parent in order to parent their child.” (Children's bereavement support organisation)

“Staff should also speak with the child's parent, family or carers where possible so that they are aware of how the death is being talked about at home and can reflect that in the support that they provide.” (Children's bereavement support organisation)

“Training is not about turning teachers into counsellors but equipping them to engender a bereavement-aware culture in the school environment (where children spend a significant proportion of their time) and a whole-school approach.” (Children's bereavement support organisation)

Respondents to the organisational survey also suggested educational institutions work in partnership with a range of statutory and third sector to provide support for bereaved families including the local authority for concerns around attendance, specialist Children and Young People's Mental Health Services (CYMHS), Jobcentre Plus, GPs and other service providers, including child bereavement services.

The current development of mental health support teams in England was felt to be a potential opportunity for better support. As well as providing support onsite (eg through employing a school counsellor, or providing peer-to-peer support opportunities) and signposting or referring to external organisations, there were practical things that schools could do. These included providing resources (laptop, WiFi) and interruption-free confidential space to access online support. Allowing and prioritising time out during the day to access external support was important because bereavement support organisations can need to provide support within school hours. Choice is important

here however, as some children will worry that receiving support in school makes them stand out and alerts their peers to the fact they are receiving help, and may prefer to receive this outside school.

“Schools should have bereavement specialists” (13-15 year old)

“We have seen both parents’ and schools’ reluctance to allow children to miss time at school in order to attend support sessions when they have had so much time away from school through the pandemic, yet confining all support to after school hours limits capacity for services” (Children’s bereavement support organisation)

Organisations emphasized the importance of paying careful attention to the needs of pupils with **special educational needs or disabilities including autism**, who may need particular support to understand what has happened and to express how they are feeling. Clear facts and language can help them to absorb what is happening. Working closely with the child or young person’s family can help staff provide a coherent approach and liaising with other organisations supporting the child or their family was also recommended.

In early years settings, respondents felt agreement was needed about how to manage regression and behavioural patterns, and to increase observations so as to have a clear picture of how the child is affected and any further support they might need.

Respondents felt that a whole setting approach would encompass opportunities to learn about loss, death and grief in the curriculum (see separate section on grief education), encouraging engagement in honest conversations about death and promoting healthy discussions about grief to help prepare young people for bereavements.

The outcomes that children, young people and parents wanted to see from improved support included greater acknowledgement, greater consistency in support over the short, medium and long term (including, where possible, support before the death), more flexibility, and regular check-ins which should be done discreetly and sensitively, to minimize any sense of ‘difference’ a child or young person may feel.

“Talk to you in private, not make it clear that they have just taken you for a chat because personally I think that’s gonna create a lot of attention towards you and then the question will start being asked.” (13-15 year old)

“Allowances beyond just the week after the persons death, as I felt more affected months after than right after the event” (16/17 year old)

“Understand and maybe support before their death, if the terminal illness is known as this time before they died was the hardest for me, even compared to after they died.” (16/17 year old)

“More child-centred approach would be more helpful, looking at practical aspects such as helping to catch up with any missed work due to absence or incomplete homework (since the family at home are grieving.” (Parent of 5-12 year old)

Suggested elements of a school policy included:

- Holding information about local and national sources of support for children and families, and about when and how to signpost or make referrals
- A clear process for sharing information about the bereavement so that staff are aware of the child’s circumstances and can offer consistent support over the short, medium and long term.
- The Danish Plan-B scheme was suggested as a potential model which would ensure a consistent approach, led by the young person themselves
- A whole setting approach to support with personalised support

B. Staff Training

Adults, children, young people, parents and organisations all saw training as a crucial way of improving support in both educational settings and workplaces, and help staff respond in a way appropriate to their role.

Respondents advocated for staff training on bereavement awareness, including how to support people, including flexibility around returning to work or school/college. Some organisational respondents argued for the need for official guidance, including potential webinars for employers and teachers to help them understand issues of grief.

This training would be justified by the number of bereaved people employers and teachers would likely encounter. Several organisations noted that the appetite for training had been increased by the pandemic.

Organisations highlighted that, as well as morally the right choice, it is in employers' interest to be well equipped to support employees through a bereavement, as it is cost-effective to have supportive policies, backed up by staff training and awareness in place, to mitigate lost productivity.

“All employers needs to have basic bereavement awareness training, so that they can be more supportive to their employees.” – organisational respondent

“Employers need to understand bereavement trauma (confusion, forgetfulness etc.) the long-term cost of unsupported grief (mental ill-health, resignation etc.) and be encouraged to provide flexible working patterns for difficult times.” – organisational respondent

“I think there is a general lack of understanding of how bereaved people are affected at work in the general population. On the one hand people express sympathy, on the other they suddenly demand work with a ridiculously tight deadline (etc.)”- Man in his 50s whose wife died of cancer (Scotland)

“I think that employers should realise that an individual's grief is not time limited and the effect on their mental health is also ongoing. Often dealing with the grief of a partner and finding yourself in the strange situation of being a single parent and going back to work after an extended absence is daunting and bewildering.” – Man in his 50s who whose wife died of cancer (Scotland)

Suggested topics for workplace training, especially amongst managers and HR staff included:

- a. Awareness of the experiences of grief and the long-term nature of grieving
- b. Awareness and sensitivity to different cultural and religious attitudes and practices around death and bereavement
- c. Ways to support bereaved staff
- d. Information on end-of-life planning
- e. Signposting to information and support

In relation to school settings, some felt that all staff should have this training, others that each school should have a trained bereavement lead, who might also be the key contact for individual bereaved pupils.

“If 1 in 10 children experience bereavement then teachers should have training so they recognise possible behaviour that is associated with grief such as anger or guilt” (Parent of 5-12 year old)

“There should be a trained bereavement lead in each school who has the confidence and skills to support bereaved and about-to-be-bereaved young people.” (Children’s bereavement support organisation)

*“Teachers to understand we get angry and upset, can't concentrate and can't always get organised as a lot happens and our adults have a lot to sort out, people to speak to and sometimes are crying”.
(5-12 year old)*

“Normalise their grief because a lot of children, you know, they think what I’m feeling isn’t normal and just to be able to have that conversation with children”. (Children’s bereavement support organisation)

“Recognising that the end of term is not a magic watershed after which bereavement needs disappear, and that children can be significantly impacted by bereavement that happened some time ago” (Children’s bereavement support organisation)

Suggested topics for staff training in schools included:

- Knowledge of children’s understanding of death, common grief reactions and behavioural responses at different developmental stages and in different circumstances (including suicide and military death).
- Knowledge of how bereavement affects the whole family and the impact this might have on parenting and family dynamics.
- How to provide an immediate response and to help normalise a child’s grief.
- Awareness of the long-term nature of grief and the need for continued support, and an appreciation that children revisit their grief with new understanding as they mature developmentally, gain a fuller understanding of concepts of death and the meaning of their bereavement, and face further transitions in their life such as the move to secondary school.
- How to spot when a child or family might need additional support, and how to access this.

C. Cultural change

Reflecting, and underpinning, the need for a whole setting approach in schools and colleges, respondents, as well as participants in the oral evidence, highlighted the need for more compassionate, supportive schools, colleges and workplaces. It was felt that employer and staff support needs to be more than just a policy and that workplaces and education settings should seek to creating a culture at work where people feel safe, comfortable and supported as part of their commitment to staff and student wellbeing.

“About active listening-line managers, whether it’s bereavement, whether it’s a mental health issue, an employee should be able to talk to your line manager who should at least have the signposting ability to point to the appropriate pathway.”- Oral evidence

“Having that psychologically safe employer employee conversation and then keeping in touch, ‘how are you doing?, What are you doing?’ ...Need to be able to normalise talking about death, taking an inclusive approach, fits as a strand of an employer’s wellbeing strategy.” - Oral evidence

Workplaces and education settings are where many people spend a large amount of their time and serve as a crucial support network for people without a family. Respondents also felt that these settings could serve as a starting point for precipitating a wider cultural shift (discussed in the previous chapter).

Wider societal initiatives outlined in the previous chapter, to advance understanding of, and normalize conversations about dying, death and bereavement, would also help hugely to improve support within educational settings and workplaces.

“I think it is incredibly important to reiterate to a bereaved person that they have people they can turn too as not everyone is a lucky to have a supportive family like I do. I think initiatives through workplaces would be an excellent idea.”- Woman in her 40s whose husband died of cancer (England)

“I think bereavement needs to be talked about openly and maybe normalising it more in schools and workplaces would help.” – Woman in her 60s whose husband died of cancer (England)

Conclusions and recommendations to improve support in workplaces and education settings

As the places where adults, children and young people spend a large proportion of their time, it is crucial that education settings and workplaces get bereavement support right, but a sizeable proportion of adults, children and young people reported poor support or no support from their school, college or workplace.

Sadly the evidence shows that there is still a long way to go to ensuring bereaved people are adequately supported in these important contexts.

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 schools and other education settings should be required to have a bereavement policy including staff training, and a process for supporting a bereaved child and their family

While the first two chapters of this report have addressed the immediate communities around bereaved people, the following three chapters concern the settings that bereaved people encounter because of their bereavement

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 WHO LOST HER MOTHER TO 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 their loved ones, receive around the time of death has a profound impact on long-term experiences of grief. Effective end of life care, through timely assessment where a death is expected, appropriate medical care and social care, frequent communication, and access to early and appropriate emotional and bereavement support, improves the quality of life of the dying person and those important to them.

Currently, the care and support received at the time of a death varies enormously.

Key findings:

- Respondents reported huge variation in the care and support they received from professionals around the time of death, with perceived inequalities across different settings, between different population groups, and between different types of death. Respondents to the Commission inquiry whose relative died suddenly; died in a hospital or care home; or was from ethnic or religious minority background consistently identified short fallings in the care they received around the death. The pandemic also exacerbated these issues.
- Factors associated with good support included culturally sensitive advance care planning, high quality and holistic end of life care, good communication, contact with the person who died and continuity of care.
- The pandemic profoundly disrupted experiences around death. Among respondents bereaved during the pandemic:
 - 65% of respondents reported difficulties with limited contact with their loved ones
 - 54% said they were unable to say goodbye as they wanted
 - 52% said they were not physically present when their loved one died
 - 42% said they experienced a lack of support from professionals

- Requirements for change identified in the evidence included:
 - Facilitating advance care planning
 - Improved support for sudden deaths
 - Increased continuity of care
 - Greater religious and cultural sensitivity
 - Professional training in bereavement
 - Balancing infection control with wellbeing considerations in future pandemics

This chapter explores experiences of support from professionals around the time of death. The first section identifies some of the characteristics of a good end of life experience; the second section explores barriers to this including impacts of the pandemic; and the final section outlines suggestions and key recommendations for change.



What helped at the end of life

Respondents identified a range of factors across different settings that contributed to good support around the time of death for both the bereaved and the person who died.

A. Culturally sensitive advance care planning at end of life

Where a death is expected, organisational respondents highlighted the importance of advance care planning for both the person at the end of their life and their families (including children and young people), to facilitate psychological and practical preparedness for the death. Better preparedness can alleviate anxiety, improve quality of time at end of life and make the process of adjusting and sorting out affairs post-death less stressful. The oral evidence highlighted the importance of cultural and religious sensitivity in this process. Examples of good advance care planning in palliative care included consulting patients and their families about the place of death, as well as sensitivity to religious requirements, such as quick burial for the Jewish and Muslim communities and cultural differences regarding attitudes to determining the cause of death.

“I guess it starts off with the patient and actually what they would like to happen to them when they are dying, and knowing their preferred place of death. Sometimes even though they do come into hospital, they would prefer to die at home or they would prefer to die in a hospice, so it’s about engaging the patient initially. Whether there is any religious or even cultural needs that they would like performing when somebody is dying. For the Jewish and Muslim community, things like expediting paperwork, death certificates, making sure that if the coroners do get involved that there’s a quick response. If there’s a post mortem here within London, we’ve set up an alternative where people can have a CT scan or MRI scan to find the cause of death. Some people within our community they don’t really understand the notion of why do we actually need to know the cause of death. Somebody’s died, and we accept it, but legally speaking in this country, we need to write down something on the death certificate as cause of death, and it’s just kind of engaging the community in terms of what their cultural needs are.” – Oral evidence

“We worked out a plan and a programme to enable us to make changes in the home to enable her to come out [of hospital]” – Oral evidence

B. High quality and holistic end of life care

Respondents particularly valued good medical care, including pain control.

“I feel so grateful to know that he wasn’t in pain” – Woman in her 60s whose husband died of cancer (Wales)

They also highlighted the importance of holistic end of life care, addressing all their relative and family’s medical, practical and emotional needs. Small acts of warmth and kindness from healthcare staff such as hugs at distressing moments were greatly appreciated. Individuals described some hospices as going “above and beyond” in their holistic approach to palliative and end of life care, showing families real emotional support and guidance.

“One [out of hours] nurse actually hugged me and asked if I was okay and I will always remember that act of human warmth.” - Woman in her 70s whose husband/partner to cancer (England)

“We had amazing care shown to us by the hospice as family members, real emotional support and guidance.” - Woman in her 30s whose mother died of cancer (England)

The evidence also highlighted situations holistic care was provided using models of effective multi-disciplinary team (MDT) approaches in primary care. For example, making use of counsellors and social workers. A Kingston based initiative identifies locally available community-based support that can be connected with healthcare organisations.

C. Good communication at the end of life

Survey respondents highlighted the value of good communication from health and care professionals both before and immediately after the death. This included being able to visit the person who was dying; feeling they were kept well-informed about their condition, care and treatment (where relevant); access to an explanation about the cause of death if desired; compassionate conversations; and timely provision of bereavement support and information.

Individual respondents and oral evidence participants highlighted examples of good support from hospital chaplains and medical examiners who provided explanations and compassionate conversations. Specific examples included: calls with the healthcare team; an effective home discharge plan; and during the pandemic, a video link up with a spiritual care provider and family prior to death.

“But we did have chaplaincy, we had medical examiners explaining causes of death, and after support with compassion packs and comfort, compassionate conversations and phone calls, which perhaps we wouldn’t get in the home setting necessarily.” – Oral evidence

D. Contact with the dying person at end of life

Both individual and organisational respondents emphasised the value and importance of contact with the person around the time of death and the role of this in a ‘good death’ and ‘good grieving’. This included being able to see the person before they died, being with them at the time of death, including the possibility for physical contact such as holding their hand or being able to say goodbye after they died.

“Thankfully, with PPE I was able to be with my loved ones when they passed away.” – Woman in her 40s whose father, mother and aunt/uncle all died (England)

“I was able to be with her when she died as she was at home & in my bubble” – Woman in her 60s whose mother died of COVID-19 (England)

Respondents valued when health care staff had supported this by allowing frequent visits and facilitating regular phone calls or video calls where in-person visiting was not possible. Participants highlighted how this enabled family members across the world to be present.

“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” – oral evidence

While contact around the time of death was often more difficult in the context of sudden or unexpected deaths, the oral evidence highlighted an ambulance initiative to encourage ambulance staff to invite families in before finishing the resuscitation attempt so they could be present at the moment of death.

E. Continuity of care

Adult respondents also mentioned the value of continuity of care from before to after the death when a death was expected. The evidence highlighted that hospices tend to have more integrated pathways and offer more continuity of care from pre-bereavement through to support after death for families than other end of life settings. Many provide follow-up contact and offering a range of support options for families.

“My husband died whilst my mum was terminally ill and under the care of my local hospice. Their family support team have supported me since he died and continue to support me even after my mother’s death.” - Woman in her 40s whose husband died due to a brain haemorrhage (England)

“I received support from the counsellor at the local hospice for 6 months prior to death and after. This was great as I effectively ‘lost’ my husband a long time before he died and the support was available at each stage of deterioration.” – Woman in her 60s whose husband died of cancer (England)

“I think hospices have quite joined-up pathways in terms of they have pre-bereavement support, people generally receive follow-up contact, and then they’ll generally be bereavement series that they can access if they want which they should be given information about, and hospices can do

other things like bereavement information in evenings. They do offer a range of support, and there is quite a clear pathway.” – Oral evidence

Witnesses who gave oral evidence shared examples of good practice for deaths in hospital settings too. One example was of hospitals following up with families and connecting them with bereavement support programs. Participants highlighted that in Northern Ireland there is a hospital-based bereavement support programme where coordinators follow up with families to reassure them that loved-one didn't die alone and provide families with helpful booklets.

“We have a huge amount of people that suddenly die with us, but we do have a dedicated team that will phone up. I suppose it's the pre-bereavement, because we have such a vast area, but certainly post-bereavement, but then sometimes it's the scenarios at end-of-life and bereavement that will impact on the bereavement experience, so in a way, we need to sort of extend that, but we do link in with Cruse and our local hospices post-pandemic at getting more engaged in how can we help support, which is brilliant, so I think if there's one thing that's positive out of COVID-19, it is that people's willingness to join up and actually getting end of life and bereavement recognised a little bit more than it has been.” – Oral evidence

For people whose primary contact with a professional after the death is a GP, oral evidence participants pointed out that in Northern Ireland they are developing a pathway to go on GPNI websites. They reported that GPs are very supportive of learning and working with people but need to know where to signpost people to, so the new hub and website will be an extremely valuable tool.

Barriers to receiving support at end of life

A. Variability between end of life settings

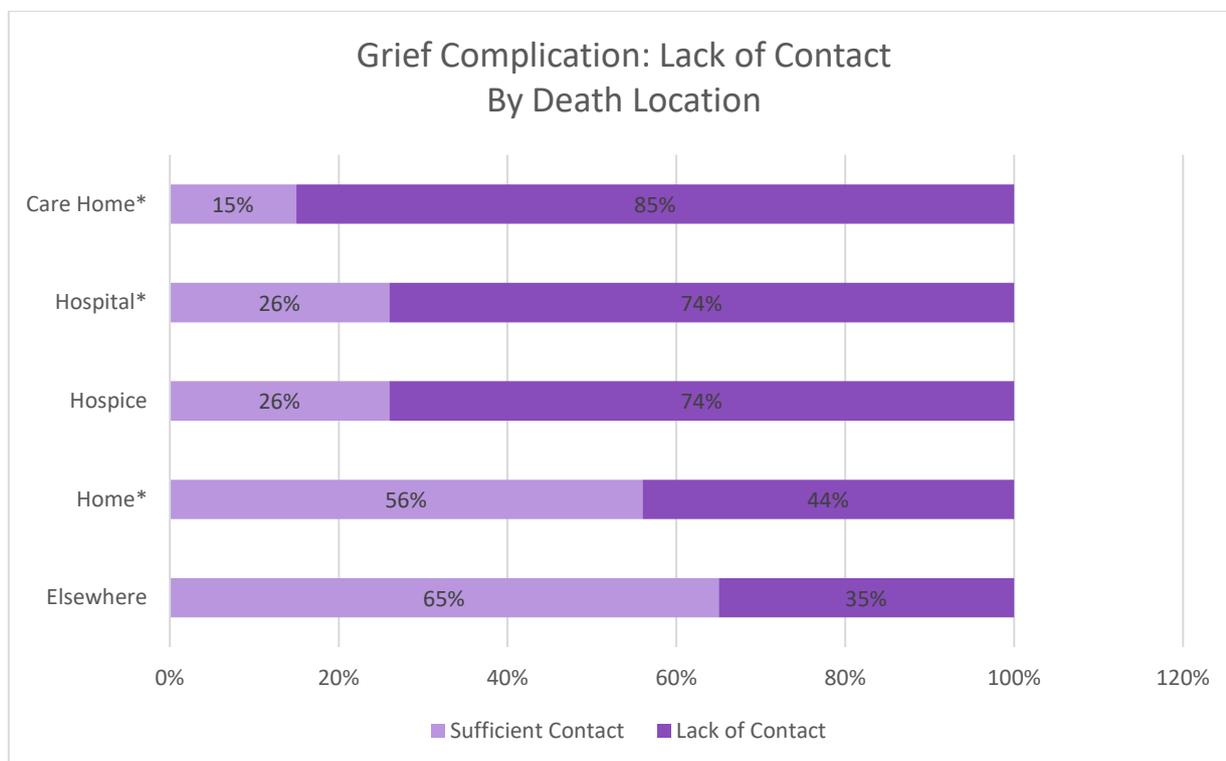
The oral evidence highlighted the variability in support between different settings and by cause of death regarding the care both the deceased and their family received around the time of death, including signposting to bereavement information and support after the death.

While there were positive and negative experiences in all settings, deaths that occurred in hospitals or care homes, and deaths that were unexpected, had a lower likelihood of the bereaved person being involved in care decisions and feeling well-supported after the death, compared to expected deaths and those in hospices or at home.

In the quantitative data, it was observed that, during COVID-19, most people who were bereaved by someone dying in hospital or in a care home, had their grief complicated by being unable to say goodbye⁷ and having a lack of contact⁸ with the person before their death. People who were bereaved by someone who died in their own home were significantly less likely to have their grief complicated by lack of contact or being unable to say goodbye.

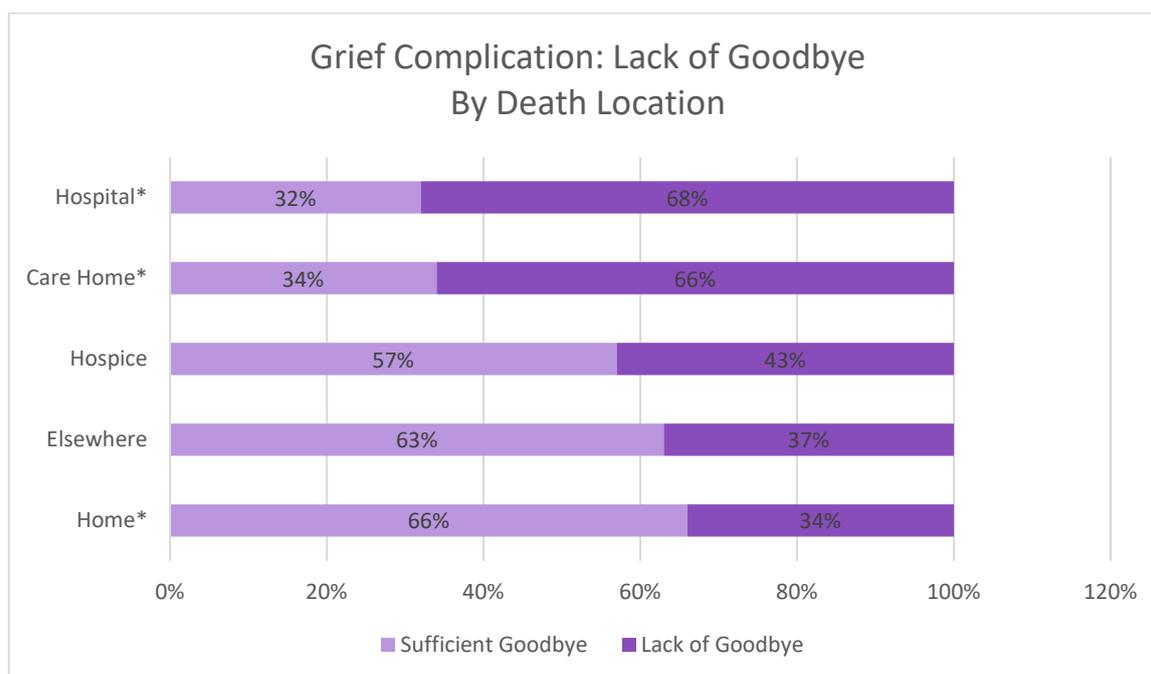
⁷ $\chi^2(4) = 68.28, p < .001, \phi_c = .30$

⁸ $\chi^2(4) = 85.56, p < .001, \phi_c = .34$



*Statistically significant finding as explained in text.

N = 652



*Statistically significant finding as explained in text.

N = 652

“The care provider didn’t recognise the dying process, escalate to family to enable them to have quality time prior to death. Really poor communication between care home/Hospital and wife. This has had a massive impact on the grieving process and bereavement care.”- Woman in her 50s whose friend died of a terminal illness (England)

Some respondents whose relative had died in hospital said they felt let down and unsupported by health care professionals, reporting that the hospital staff they interacted with failed to provide adequate care to their loved

one and seemed desensitised to death including not providing any emotional support to them as a bereaved relative.

“I think in a case like mine the hospital not only let my husband down but they did absolutely nothing to support me and my family. It was just tough was the impression we had it was very cool and calculating with absolutely no empathy whatsoever.”
– Woman in her 80s whose husband died of heart disease (England)

“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

“You go from a hospital that has a fantastic psychological team that can help support families getting to that stage towards end of life, and on the flip side there are other trusts that absolutely don’t have that or need to farm out to charities that don’t exist anymore, who have closed down because of pandemics, and so it is about access, inequality of access for a thousand reasons, but yes, it’s all compounded by thinking in not a linear picture within services of pre- and post-bereavement really.” Organisational response

The evidence highlighted particular difficulties for bereaved people in receiving support from professionals when a death was unexpected. Oral participants emphasised how emergency contexts made it much harder for the professionals involved, such as ambulance clinicians, to support families, as the professionals have no prior relationship with or knowledge of the patient and family.

For people who had died suddenly or unexpectedly, sometimes the only professional their family or friends were in contact with at the time of death was a police officer or paramedic. Respondents expressed a view that this was not necessarily the most appropriate, or appropriately trained, professional to support them at the time, and in some cases reported poor communication skills and an insensitive manner.

“I think for the ambulance service the issues are about the fact that the ambulance clinicians have no relationship with the family, patient and the family. They really don’t know them. They’re going in there blind. They’re trying very quickly to establish what’s going on. They have very little information given to them. Often they have got e-packs available to them, the electronic advanced care planning system, which if they do, there’s not available all over the country available to them electronically, but they may have that, but otherwise they have no relationship. They don’t know what the set up has been, and they don’t understand the journey that the patient and the family have gone through, so I think that that creates quite a few challenges for them.” – oral evidence

“I think the people that really miss out are people that lose family members maybe unexpectedly or in hospital settings where there’s not the same pathways. People quite often don’t receive follow-up contact, in our survey, which I know will be different because it was done in the pandemic. I think it was about less than half of people received follow-up contact from the healthcare provider, and only a third of people received information about bereavement services, so you can see where there’s really missing pathways, especially in particular settings. I think in care homes, people were least likely to receive any kind of information around bereavement support if their loved ones died in care homes, so I think it varies between settings.” - oral evidence

“We were not given a liaison person - months later I was told it was a police officer who had been very unhelpful in his phone calls after my daughter’s death. He is not the person who should be contacting bereaved parents following the sudden unexplained death of a child (my daughter died in her sleep at her childminder’s during an afternoon nap). The policeman was insensitive, a poor communicator and did not know about the forms he was asking us to fill in. We needed to be supported by more appropriate (or appropriately trained) professionals eg doctors, Coroner’s

officers, paediatricians.” - Woman in her 30s, who whose daughter died of sudden unexpected death in childhood (England)

“The police need additional training and support delivering the news to loved ones who have been in a sudden and traumatic death” - Woman in her 60s whose partner died of cancer (England)

“The police made contact but this was in relation to the investigation, no emotional support was offered.” - Woman in her 50s, whose son died in an accident (England)

Strained and inadequate services

Driving the variation in experiences of care at the end of life, some respondents felt that many services were strained to the point of being unable to deliver access to quality care both before and after death. For example, some adults who responded to the consultation described that their grief had been worsened by the fact their relative did not have access to palliative care.

“My grief has been compounded by their constant refusal to see my husband in person and therefore to recognise that he was deteriorating to the point where palliative care should have been offered. We were never offered anything except the opportunity to sign a Do Not Resuscitate Form - No Hospice contact or advice - No Palliative Nursing Care - nothing to recognise that we were in crisis in our home and so my husband suffocated alone in a side ward” - Woman in her 60s whose husband died of a terminal illness (Northern Ireland)

Oral evidence participants warned of the ‘moral injury’ caused to both families and health care professionals by unacceptable treatment of patients in hospitals, for example people dying in hospital corridors prior to admission to ward, or not receiving essential care and pain relief. Participants reported different experiences depending on hospital facilities and resources.

“I see this now nothing to do with COVID-19 but for people dying in corridors waiting to be admitted moral injury that the [emergency departments] and medical consultants are facing, I think you know, there has to be a conversation around dignified death as well, in terms of our trusts are under pressure.”- oral evidence, Northern Ireland

“If I wasn’t a nurse and if I didn’t have my training as an end of life doula I dread to think what care my mum would have received at the end of her life. Knowing she had a good death really helped with my bereavement” - Woman in her 50s whose mother died of frailty (England)

“Every available service in health and care is linked to funding. There was no dignity in my ex- husband's death. It was an ugly, agonising, tortured end which our children witnessed and which healthcare professionals did little if anything to prevent.” - Woman in her 60s whose husband died of cancer (England)

The oral evidence also specifically highlighted that there was no paediatric pathology service in Northern Ireland, meaning a deceased child’s body is transferred to England for a post-mortem. This was felt to be inhumane in the context of a child’s death.

B. Cultural insensitivity and inequalities at end of life

Oral evidence highlighted insufficient cultural sensitivity training among white care providers. Participants gave examples of racial discrimination, cultural insensitivity and lack of dignity in end-of-life care provided to dying family members.

Respondents also felt there was a shortage of black end of life doulas, and a need for more cultural competency amongst some white end of life doulas.

Organisational participants also reported difficulties with 'gatekeepers' (e.g. receptionists) including bereaved people reporting they experienced insensitivity, and were on the receiving end of bureaucratic rules and processes when they tried to arrange medical appointments. This caused frustration, conflict and sometimes perceptions of differential treatment relating to their ethnic background.

"Trying to arrange an Islamic funeral and finding a general lack of knowledge of our rituals and requirements within the personnel at the hospital." - Woman in her 30s whose mother died of organ failure (England)

"He was an elderly person and for those who know elderly Caribbean folks, they speak in particular ways, they have particular nuances, they have particular likes and dislikes and you almost can't budge them. They were used to certain things and certain people around them, visitation was limited, and so, the comfort wasn't there. His way of talking, when she was explaining it to us made perfect sense, it made perfect sense, but those around him were treating him like he had no sense. Her thoughts was her father said to her, "Them thinks me an idiot" right, and you know that coming from someone who is feeling that they are not being heard. And so, there is this sense about the insensitivity." – oral evidence

"Prior to my mother's passing, I repeatedly requested an Alimah (Muslim equivalent to Christian Priest) to visit at the hospital. The hospital personnel, and the bereavement team only had contact details for a male priest and were unable to help, or even exert the effort to accommodate. Having access to an Alimah would have been of tremendous assistance. She would have been able to provide spiritual guidance to our mother, before her passing and would have been able to provide practical advice to me on processes." - Woman in her 30s whose mother died of organ failure (England)

The oral evidence additionally highlighted research findings that people with higher levels of qualification felt better supported by health care professionals following death and were more likely to be contacted by care providers after death.⁹

Some young respondents also felt that their needs had been overlooked around the death, including before the death of the person they knew, which they found very difficult.

"This time before they died was the hardest for me, even compared to after they died." (16-17 year old)

C. Pandemic-related difficulties

Survey respondents were affected by a huge number of pandemic-related difficulties relating to COVID-19 restrictions and the context of mass bereavement. Bereavement due to COVID-19 compared with all other types of death decreased the likelihood of being involved in care decisions and of feeling well-supported by healthcare professionals after the death and increased the likelihood of being unable to say goodbye.¹⁰

28% of adult survey respondents said they had experienced difficulties around lack of support from professionals during COVID-19.

Organisations also noted the longer-term impact on other areas of healthcare because of COVID-19, for example, scheduled treatments being cancelled which we are now seeing the consequences of delays in diagnosis/treatment.

⁹ Selman et al. 2022, Risk factors associated with poorer experiences of end-of-life care and challenges in early bereavement: Results of a national online survey of people bereaved during the COVID-19 pandemic. Palliative Medicine <https://journals.sagepub.com/doi/10.1177/02692163221074876?icid=int.sj-related-articles.citing-articles.1>

¹⁰ Ibid

Impact on Advance Care Planning

Planning around the death, which is linked with better outcomes for bereaved individuals, was disrupted by the pandemic too. During the pandemic, families were less involved in planning for end-of-life care by health and care services and in general, there were fewer opportunities for advance care planning.

Patients and families who had Advance Care Plans were sometimes unable to act on them, including their place of care preferences due to the pandemic, impacting on family bereavement experience. Some chaplains found it harder to help prepare families for the death when unable to visit or spend time at the bedside and found that some cultural groups are less prepared than others.

“We've been asking people to plan for their end of life and talk about what kind of end of life they would like you know, at home, in the community, with family and friends, so lots of people who've kind of developed end of life kind of plan, haven't been able to implement those plans over the last 18 months and the impact that's had on the and their families.” –Scotland roundtable

“People who had long term and terminal illnesses pre pandemic. Their family in their head had an expectation and plan how they wanted it go and obviously the pandemic swept that away from people.” – England roundtable

Impact on community-based care

“The continuity of care was disrupted by no day care/ fewer staff visiting homes/ lack of co-ordination between community services which had a direct impact on end of life care and therefore an indirect effect on bereavement. My daughter who works in the NHS has struggled with returning to work due to witnessing poor pain control & what she considers as the NHS letting down her dad in his last days”

Oral evidence witnesses reported that families did not always receive enough support from GPs, including essential equipment when providing care at home during pandemic. The pandemic also impacted on community-based palliative care. Hospices highlighted that home visits were conducted by multiple professionals, and there was a lack of human connection and human touch.

“There's so many people that are suffering from anger over the way that the GPs are treating them and you know, some of these stories are so tragic where you've got the doctor completely ignoring, doing anything about it. They're even asking when can they please go and buy their own equipment and not getting any help, nebulizers and then the person dies in front of one another sort of thing. It's so terrible.” – Inter-faith roundtable

“I think from a hospice's point of view, many of our hospices obviously work in the community. I think it's also been the lack of human connection and human touch. It's all had to be remote. A lot of families out in the community were used to having multiple professionals come to the home and offer that support, which became quickly inexistent unless it was over a Zoom call.” – Oral evidence

Impact on communication at end of life

The evidence submitted demonstrated wide variation in end-of-life care in terms of extent to which relatives felt involved in decisions that were made, felt informed about approaching death, and felt supported after the death. Only 35% of adult respondents said they felt supported after the death. Communication problems described included difficulty getting information about their family member, being misinformed about their condition or hospital policies, and not being involved in care or treatment decisions. Over half of children and young people who shared their thoughts with the commission, which includes those bereaved before and during the pandemic, (54%) reported experiencing difficulties around lack of support or unclear communication.

“We had the restrictions, the visiting, the communication over the phone, and an unfamiliar environment...And if family were in, and we did try our best, but again it was the use of PPE, so they’re all barriers there.” – Oral evidence

Individual and organisational respondents highlighted that hospital/care staff did not explain the cause of death to families and there was a general lack of communication leading to more post-mortems and coronial investigations. Organisations also described life-changing news being delivered to people alone when unable to be accompanied for hospital appointments or being delivered via telephone or iPad, causing distress and meaning people were not adequately supported around this time. Parents and pregnant mothers were forced to receive news of their children’s deaths alone and were not provided with support or information about what would happen next.

Participants also reported problems caused by Do not attempt CPRs (DNACPs) being used inappropriately and not sufficiently explained to families by staff who were not equipped to have these conversations. This had lasting impacts on family grief.

“Colleagues sharing round the table of incidences of where DNACPRs were not used appropriately and staff were not equipped to have those conversations which will have had a lasting impact on the families and in terms of complicating their grief as well.” – Scotland roundtable

“What we had was we put them on the phone or have an iPad or something, but even that was distraught because they would still be begging the staff members, “I just want to see my loved one once more.” And also balancing that out with actually streaming live a death process, which is sometimes I feel it’s very unethical, because somebody’s dying. it’s not something you’d want to stream out, and you don’t know where it can end up.” – Oral evidence

Impact on contact with the dying person at the end of life

Just over a third (37%) of adult respondents who were bereaved during the pandemic said they were unable to say goodbye as they wanted due to the pandemic; 43.9% of adult respondents expressed difficulties around limited contact with their loved one before the death both in homes, care homes and hospitals, with 26.8% saying they were not able to be physically present when their loved one died.

Many individuals and organisations mentioned how being separated from loved ones at the end of their life had left families feeling guilty, angry and traumatised. Being apart meant that families didn’t get a chance to spend precious time together, doing the things they had wanted to before a death (where this was expected) or to say goodbye.

“I couldn’t see them before they died because of COVID-19.” – 5-12 year old

“We were denied basic human rights... as a family member as was my mum... basic human rights to be with loved ones.. the power of family love should never be underestimated.. in every aspect.. no one knows a patient like their family...no one loves a patient like their family.. there are so many aspects of this that are traumatic.” - Woman in her 40s whose mother died of COVID-19, (England)

“A COVID-19 death is like no other I have had to experience... they were spirited away in a rush and never seen or heard from again, like some kind of abduction. No chance to see them after death.” – Woman in her 70s whose daughter died of COVID-19 (England)

Many respondents described the agony of knowing their loved one was alone when they died – some described this as the worst aspect of their bereavement experience.

“The most difficult part in all this was not being allowed to visit my Dad and thinking of him spending 9 days alone, in hospital with people he didn’t know.” – Woman in her 50s whose father died of COVID-19 (Wales)

“Most awful experience of my life and I’m horrified by how alone, afraid, restricted and distraught my Dad must have felt.” – Woman aged 18-30 whose father died of cancer (England)

An oral evidence participant (speaking with regard to families in the Bengali community in London) revealed that families stopped sending sick relatives into hospital, fearing that they wouldn’t see them again.

“I’d say within the Bengali community in London, we had a mixture of people who said they’re not going to send their loved one to the hospital, even though there were chances of they could have lived, because they were just too scared that once they go into that ambulance and those doors close, they will never see that loved person again. Early on, even after the death, there was no viewing allowed, so one of the ways that we kind of engaged with local communities to make sure that everything can be done, following the right infection control policies, using PPE and so forth.” – Oral evidence

The different rules in different parts of the country and in different settings increased the resentment that some individuals felt.

“I feel incredibly angry and bitter that my sister and I were not allowed to visit our dad during his weeks in a local hospice before he died (COVID-19 restrictions) this rule didn’t seem universal across the country making it very unfair on those of us that were robbed of this precious time” – Woman in her 40s whose father died of cancer (England)

Some organisations felt that children had been particularly excluded from these opportunities.

“Children are often referred to as ‘forgotten mourners’: it has become clear that throughout the pandemic that it has been harder to ensure children’s voices have been heard and their needs considered in discussions around addressing emerging difficulties, such as not being able to visit people who are ill, seeing relatives before they die etc.” – Children’s bereavement support organisation

Children and young people had been exposed to traumatic deaths, whether or not they were present when the person died. Organisations expressed concern about the possibility of delayed grief and delayed trauma on children and young people – as explored in the first chapter.

Impact on Rituals

The oral evidence highlighted the detrimental impact of pandemic restrictions on religious rituals, emphasising that minority faith leaders were prevented from visiting dying patients and families in hospital and unable to complete traditions and obligations. This caused a lot of difficulties for people from those communities.

“Some of our local communities and not being able to carry out rituals, traditions, obligations that perhaps, well obviously would have been done in usual things, and I’m thinking from the hospital perspective around rapid release and registration, and I know that that caused a lot of difficulties for our local communities.” – oral evidence

Change needed

A. Improved Advance Care Planning

Palliative care staff should take holistic and culturally informed approach to assessment of risk factors and coping styles and should be willing to start conversations about planning for death early.

Equally important is ensuring advance care plans and wishes are respected so that a ‘good death’ is possible. Participants suggested the benefit of a digital record of a person’s wishes that follows them throughout health and care settings.

Respondents based in Scotland specifically suggested developing a **strategy for anticipatory care planning in the nation.**

B. Better support for sudden deaths

It is crucial that people who experience sudden deaths are able to access appropriate bereavement support, recognising that they may have minimal contact with health and social care services but often complex needs.

Sudden deaths include unexpected child and adult deaths, deaths by suicide, pregnancy loss and stillbirth. As some sudden deaths involve an A&E admission one suggestion was for referrals from A&E services to bereavement services.

“Referrals in A and E services for example to bereavement support after a sudden death.” – Scotland roundtable

C. Greater continuity of care

Where deaths are expected, respondents and participants made recommendations about establishing continuity of care, through follow-up bereavement calls and signposting to further support if needed. This could help to address feelings of abandonment by healthcare teams following the death.

Below are recommendations for hospitals, GPs and the healthcare system as a whole

Suggestions for hospitals

- Having a trust governor or non-executive director with a bereavement role
- Bereavement support teams or a bereavement office in every hospital to explain practical next steps and signpost to emotional support
- Family liaison officers, a social worker or welfare office present in all health and social care settings to provide support pre- and post-death.
- Hospitals to take a role in assessment of holistic support needs.
- Acute hospitals to maintain a sustainable bereavement aftercare service as some were doing in COVID-19.

“There should be the same level of bereavement support available for all bereaved people that is given to bereavement of individuals known to a hospice and this is just not out there. All hospitals should have a bereavement support team, not just a bereavement officer.” – organisational respondent

Suggestions for GP services

- Take a role in assessment of holistic support needs following a bereavement – including assessing for psychiatric illness where death more traumatic bereaved parents
- Start conversations about expected deaths – including what to do next.
- Follow up appointments or check ins with people particularly at risk of adverse bereavement outcomes.

“We need to consider how we can improve the ways we proactively identify those at risk of adverse bereavement outcomes.” – organisational respondent

Suggestions for healthcare settings overall

- More joined up working and communication between hospital departments and different health settings so that (for example) GPs are informed of bereavements occurring in hospital
- Building on partnership working between statutory services and the third sector, which increased during the pandemic
- A mechanism for proactively identifying people who are at greater risk of adverse bereavement outcomes. Palliative care staff should take a holistic and culturally informed approach to assessing risk factors and coping styles.
- ambulance staff referring patients to bereavement counsellors

“One thing I desperately want to see is family liaison officers in situ in all NHS and social care organisations - I think that should be mandated.” – organisational respondent

“There should be a robust system for follow-up appointments with GPs/local social team following discharge from hospital. This is particularly needed due to the risk of mental health issues developing after pregnancy loss in terms of depression, anxiety and post-traumatic stress.” – organisational respondent

D. Cultural and religious sensitivity

The oral evidence reported the need for a multi-faith chaplaincy so people have access someone of their own faith as needed.

Participants suggested that chaplain services could play a role in developing relationships with families and connecting with trusted community-based support after the death. This could help to overcome some of the stigma and anxiety associated with asking for help.

Participants also suggested a role for inter-faith forums and community volunteers in connecting families and communities with healthcare organisations, which could be expanded to improve signposting to local support.

E. Training for health and social care staff and emergency services

In order to support all of the above changes, organisational and adult respondents to the commission both suggested mandatory bereavement training for all health and social care staff and emergency services. Oral evidence participants in Northern Ireland reported that some GPs in the nation recognise their lack of awareness, knowledge and skill in this area and are seeking support around this. Some respondents suggested that a specialism in bereavement for mental health staff should be encouraged and facilitated.

Suggested topics for training

- Emotional intelligence and communication skills
- Holding difficult end of life conversations
- Awareness of different religious and cultural practices such as expedited paperwork and death registration process for Jewish and Muslim communities (and how to support underserved communities) including guidance for ambulance service to find out about cultural and religious needs of families
- Equality and diversity
- How to have conversations about advance/ end of life planning and palliative care principles
- How to give advice about practical processes
- How to talk to people about emotional support
- What healthy grieving looks like at different ages, how to spot signs of trauma/ prolonged grief
- How to signpost or refer people for further support
- Modules on specific forms of bereavement e.g. bereavement by suicide, pregnancy and child loss.
- Training on self-awareness and self-support strategies to maintain resilience and wellbeing and reduce potential for compassion fatigue or burnout.

“I think it would be useful for all staff to have training. Training that includes theories which gives a rationale and skills to work with the bereaved as I know where I work staff find it difficult to be with those

overwhelming and unpredictable feelings of the bereaved.” – organisational respondent

“There needs to be sensitivity around diverse cultures and faiths with regard to bereavement; more training would definitely help for health and social care staff so that they can support the bereaved.” – organisational respondent

Respondents highlighted that training needs resource and should be part of ongoing development opportunities related to bereavement.

“Access to training that is affordable, access to training that is appropriate, for example, with the training around death doulas, this is something that the guidance-- support workers in school, they should be aware of some of the things as career options.”- oral evidence

F. Balancing infection control with mental health and wellbeing considerations

Respondents felt that in similar future scenarios to the COVID-19 pandemic, more emphasis and consideration should be given to the impact on mental health and wellbeing. Some respondents spoke of human contact around the time of death as a human right.

“Giving every human being the right to say goodbye.” Woman in her 50s whose mother died of COVID-19 (England)

Conclusion and recommendations

The care for a dying person and their relatives before and during a death is incredibly important to bereaved people’s experiences of grief. Well resourced, holistic health and social care; a chance to be with the dying person and to honour their religious and cultural rituals at the time of death; timely communication from staff involved; and continuity of care can all contribute to a good end of life experience for bereaved people and the dying person.

Sadly, the evidence highlighted that in many different settings and circumstances people do not always receive the support they need at the time of death. Further, existing inequalities and inadequacies in support have been further exacerbated during the pandemic by the dual challenges of increasingly strained services and intensive restrictions.

Reflecting these shortfalls, we are calling for the following changes:

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.

While this chapter has discussed support from organisations and settings that bereaved people may be exposed to before and during a death, the next chapter looks at those people encounter during their bereavement.



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 all died (England)

“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 –19 (England)

The previous chapters outlined the emotional devastation of bereavement, and difficulties navigating responsibilities in work, school and home. In addition to these challenges, however, adults also face many new practical and administrative responsibilities and tasks after a bereavement, which are often both complex and time sensitive.

These include death registration, notifying a wide range of companies from banks and energy suppliers to the Council and social media sites, legal processes and the coronial process.

As the quotes illustrate, bereaved people often face dual stresses of feeling under significant pressures to complete paperwork on the one hand and being held up by frustrating delays and inefficiencies from some organisations involved on the other.

Key findings:

- 61% of adult survey respondents with administrative responsibilities reported difficulties with at least one of these tasks
- 39% of respondents had difficulty sorting out financial affairs
- 22% had difficulty with funeral arrangements
- 21% had difficulties registering the death
- 10% had difficulties with other practical responsibilities
- Respondents reported difficulties at all stages of death administration
- Challenges included not knowing what to do; feeling overwhelmed by both the volume and complexity of tasks; feeling under time pressure to complete tasks; and facing inefficiencies and delays from organisations.
- Initiatives and organisations working to increase advance planning, to simplify and streamline administrative processes and to offer guidance through these processes are all helpful but currently do not go far enough
- Respondents' suggestions for change included: streamlining death administration overall, and simplifying processes at each touchpoint

The first section of this chapter explores examples of what people have found helpful when it came to death administration; the second section outlines challenges and difficulties people face, both generally and during different processes; and the final section explores what could help improve bereaved people's experiences of paperwork after and outlines the Commission's recommendations.

What Helped with administration after a death

Advance care planning

As described in the previous chapter, where individuals had had conversations with their families about the wishes of the person who had died, they found this very helpful in assisting decisions around death administration such as financial affairs.

“It was fortuitous that both my father and mother had bought pre-paid funeral plans which alleviated much of the decision-making that would have been quite traumatic after their deaths. My mother had also planned her funeral service in advance and this also avoided any (potential) family disputes over what may or may not have been her preferences.” - Woman in her 50s whose mother died of cancer (England)

Organisational respondents highlighted Free Will Writing Month and Dying Matters Week as good initiatives to promote advance care planning as well as a Later Life Planning pack produced by Doncaster Metropolitan Borough Council that covers preparing for a bereavement.

Free Wills Month

Free Wills Month is an initiative run by a group of charities offering members of the public over 55 the chance to have their simple Wills written or updated for free, using participating solicitors across England, Northern Ireland and Wales

Simplicity in death administration

Organisational and individual respondents to the commission’s call for evidence highlighted a range of examples of initiatives which promoted greater efficiency in death administration.

The pandemic had led to an online death registration process which some found easier, both logistically and emotionally- though not everybody had online access. More widely organisations highlighted the technological advances during the pandemic resulting from the need to adapt and make changes quickly to address problems. They felt this had resulted in some positive progress.

“So I think it’s about taking best practice wherever we find it and putting it into the ideas box and saying, is this practical? We have shown through COVID-19 we can get things done quickly, so let’s take all the best ideas and do it.” – Oral evidence

“Registering deaths virtually was such a help. I don’t / didn’t live close by my parents and I would have had to return (200 mile round trip) to register their deaths otherwise.” - Woman in her 50s whose mother and father both died (England)

People who were able to access the ‘Tell us Once’ service, which streamlines the notification of public bodies when someone dies, valued the reduction in the quantity of administrative tasks and number of painful telephone conversations they needed to have. Respondents generally reported it was helpful and easy to use.

“Most useful – particularly the ‘tell us once’ process which sorted passport and other details very easily.” - Man in his 60s whose wife died of cancer (England)

“It helped that a lot of things could be done online, the tell us once website was a blessing as phone calls were very distressing.” - Woman in her 60s whose husband died of a stroke (England)

Organisational respondents also shared an example of good practice in accessing financial support, with the Scottish Funeral Support payments being paid directly and quickly to funeral directors without the need for means testing.

“It’s been in place at least for a year and a half if not two, and it’s working very, very well. I spoke with a funeral director just an hour ago to deal with a small issue, it’s the first one we have had in a year, and it was down to miscommunication. They seemed to have tweaked the model appropriately so that payments can be made by choice to the family or direct to the funeral director within a matter of two weeks. And that comes down to the kind of absence of means testing or the slightly different form, it just seems to work. So I would

certainly say that having gone through that experience, the Scottish model seems to be something to look toward.” – organisational respondent

Guidance through the administration process

Where people had received guidance about the practical and administrative tasks and requirements this had massively helped. One survey respondent mentioned the value of a **hospital booklet** with comprehensive guidance on steps after a bereavement including coronial processes, arrangements with the cemetery office and the registry office. In the oral evidence, the guidance published by the MND Association was highlighted as being helpful, covering all aspects, such as death registration, estate administration and probate. Some respondents also spoke positively about dedicated bereavement lines such as the HMRC probate helpline.

“Most banks and places had a dedicated bereavement line. This helped massively” – Woman in her 50s whose husband died of COVID-19 (England)

“The HMRC probate helpline were fantastic.” – Woman in her 50s whose mother died of a terminal illness (England)

“One recommendation for a charity that’s got a very good publication is the Motor Neurone Disease Association. Which has a fantastic manual which goes from diagnosis to after death, that is regularly updated, it’s a brilliant publication.” – Organisational witness in the oral evidence

Challenges and Difficulties Experienced with administration

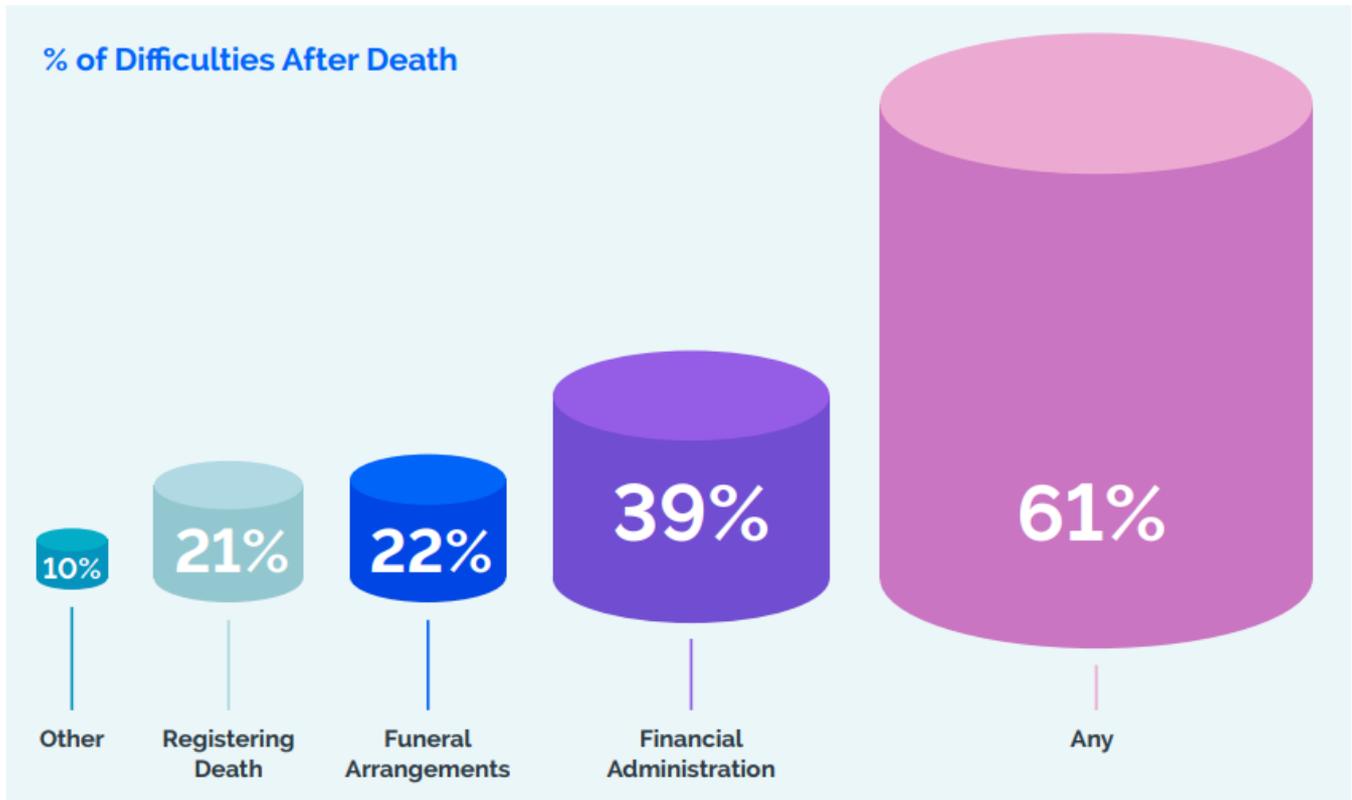
Overwhelmingly, however, respondents found the requirements around death administration to be burdensome, difficult and upsetting.

Adult survey respondents and organisations described a vast number of challenges around administration relating to death registration, financial affairs, notifying public sector organisations and utility companies.

Adult survey respondents indicated on a list what areas they personally found difficulty with, and then were given space to describe these in greater detail.

For those with practical or administrative responsibilities after a death, 61% reported they struggled with these tasks.

% of Difficulties After Death



N = 1119

One in five had difficulty registering their loved one's death



Two in five had difficulty sorting out financial affairs or arranging the funeral



One in ten had difficulties with another practical or in ten had another issue with practical or administrative tasks



Young people were also asked if they had any practical difficulties after the death of their loved one. Difficulties arranging the funeral, registering the death and sorting out practical arrangements were also experienced by young people. There was one instance each of issues with sorting through possessions, helping care for siblings, and difficulties moving house.

General challenges around administration and practical tasks after a death

1.1 Not knowing what to do

In general, people do not know what needs to be done when someone dies. Knowing where to start and finding the right information about what to do after someone dies were amongst the biggest cited challenges in the adult consultation. The lack of guidance meant bereaved people felt unsupported and lost.

“It was difficult not having a list of things that you need to sort out like cancelling drivers license and who to notify re: bank etc. Was quite a lot to fathom out.” - Woman in her 40s whose father died of cancer (Northern Ireland)

“The journey from point of death to registration, burial/cremation and the ongoing grieving process is confusing for individuals and families. Too many people (doctor/care home/medical examiner/surgery staff/coroners/registrar booking team etc) are involved and give slightly different information and this causes distress.” – organisational respondent

1.2 Feeling overwhelmed by volume and complexity of tasks

Related to the sense of not knowing what to do, a dominant theme among survey respondents was feeling overwhelmed by the volume and complexity of practical tasks, with which they received little or no support. Complex, time-consuming and duplicative administrative tasks in the days, weeks and months following a death can cause significant frustration, confusion and distress for the bereaved people responsible for these tasks.

“The sheer volume of admin is utterly overwhelming when your brain is subsumed with grief.” - Woman in her 50s whose husband died of cancer (England)

“All so confusing and when you are so exhausted it’s all a struggle.” Man in her 50s whose wife died of a terminal illness (Scotland)

1.2 Not knowing the wishes of the person who died

No knowing wishes regarding financial affairs can make decisions difficult for families and in some cases lead to tensions. There can also be practical implications if wishes are not made known and acted on e.g. in the case of unmarried, cohabiting couple who haven’t written wills and hadn’t realised that one wouldn’t automatically inherit from the other.

2 Specific difficulties around death administration and practical tasks

Individual and organisational survey respondents highlighted specific additional difficulties around different aspects of death administration.

2.1 Death Registration

21% of survey respondents responsible for death administration faced difficulties with registering a death.



Delays around registering the death were prevalent in the adult evidence with a range of reasons cited including a backlog of cases due to COVID-19, unavailability of doctors present at the death, errors on the certificate and long

waits for the coroner's inquiry. Both the adult and organisational evidence identified the negative impact of these delays on bereaved individuals, causing extreme anxiety in some cases but also having knock on effects on pensions and other allowances which continued to be paid.

"As a result of the pandemic the time between death and registration has increased, and even more so with the introduction of the Medical Examiner. Some families have contacted in a state of extreme anxiety and are frantic to know what is happening and when they can register. They have no support at that point." – organisational respondent

"Not being able to register the death by prearranged telephone appointment until 22 Sep as registrars had a backlog and were working from home. Knock on effect was that pensions/allowances etc continued to be paid because of delay in being able to officially notify them of her death. This is now being handled by solicitor and still not fully resolved." – Man in his 70s whose mother died of old age (Wales)

Registering the death in the same place as birth registration can be very distressing – especially for bereaved parents. Parents spoke of the trauma of seeing other parents celebrating their baby's birth while they registered their baby's death.

We had to register both their births and Henry's death at the same appointment. It was incredibly traumatic especially as there were people bringing in their new babies to be registered." – Woman in 30s whose son was stillborn (England)

The restrictions on unmarried partners around registering deaths was both upsetting and practically difficult in some circumstances, especially alongside there being a 5-day time limit on registration of a death. One Woman reported that she struggled to physically attend the registration appointments for her stillborn's daughter's birth and death, due to recovering from a C-section and a delayed discharge from hospital. As she was not married to her daughter's father – her partner – he was unable to complete this task.

"As partners of 20 years, and having spent the final few days at my partner's bedside, I left the room minutes before he died, to get our young daughter. Legally, as his sons were also there, they were considered priority to register his death. Registering his death, felt like it was the last thing I could do for my partner." – Woman in her 40s whose partner died of pneumonia (England)

"You have to register death within 5 days. You have to register birth before registering death. I am in an unmarried partnership so my baby's father could not register her birth or death. She was born and died on the Thursday, I was in hospital until Saturday, we got an emergency appointment to register birth and death on Monday for Tuesday. What made this challenging was I was still in a lot of pain from having a c section on Thursday and then had to get up and run about to go and register the birth with her father as apparently even though he was there at conception, during pregnancy, during her birth and at her death, he cannot register the birth because we are unmarried" - Woman aged 18-30 whose daughter died of a congenital abnormality (Northern Ireland)

Organisations working with older people highlighted the difficulties for digitally excluded people who were required to register a death online during the pandemic.

a. *Notifying organisations*

Adult respondents described the practical and emotional burdens around the sheer number of companies and organisations they had to contact in a short space of time. Participants in the oral evidence corroborated the disjointed nature of 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

“And the sorts of things we hear particularly around financial institutions, banks, building societies, insurance and utilities, gas, electric, phone, telecoms, those sorts of things, is basically people saying to us, these systems aren’t joined up. Each company does things very differently, a lot of the time it’s really difficult to find the right person to talk to within these companies or how to contact them.” – Oral evidence

Respondents found having to repeat the painful news again and again due to lack of coordination both between and within organisations very distressing and triggering. This was exacerbated by the short timescales for contacting all the organisations.

“Having to repeatedly say out loud that your wife (loved one) has died is extremely distressing.” – Man in his 40s whose mother and wife died (England)

“Incredibly harrowing to go over the same information continually when your grief is very raw, but you have a time limit to notify all parties” – Woman in her 40s whose partner/husband died of a terminal illness (England)

Some also described difficulties getting through to organisations on the phone which made already time-consuming processes even more drawn out. Those who called during the pandemic reported being on hold for a very long time.

“My Dad dealt with the aspect of sorting financial affairs. It was very distressing for him, being asked the same questions multiple times, not hearing back from companies, a lack of empathy and understanding with interactions.”- Woman in her 40s whose mother died of heart disease (England)

“I needed human contact but was abandoned. Helplines are not helpful especially when you have to spend a prolonged period on hold.” – Woman in her 60s whose husband died of COVID-19 (England)

Other respondents described how inefficiencies and administrative errors made a difficult process even more stressful. A dominant theme was feeling in the dark about the progress of the paperwork, for example information about insurance payments. Respondents expressed a sense of exasperation from having to chase companies due to administrative errors and continuing to receive correspondence after notifying of the death.

“The final payment to the energy company was very difficult, their system didn’t make it easy and it took several months to finalise, they made several mistakes and sent out 3 different final statements.” – Woman in her 50s whose father died of a terminal illness (England)

“Multiple administrative errors by bank still continuing, need to keep chasing, find it upsetting.” – Woman in her 70s whose husband died of a terminal illness (England)

“The unacceptable time frame to both have the initial conversation and also the time taken to complete the changes. 8 weeks down the line and I’m still dealing with questions and forms following John’s death.” – Woman in her 50s whose husband died of cancer (England)

“Telling EE well over 50 times that they couldn’t speak to the account holder and to stop emailing and texting a dead person (still happening today). Insurance decided to cancel car insurance after I informed of

husbands death via his email, thankfully I caught email or else I would have been driving uninsured.” – Woman in her 40s whose husband in a road traffic accident (England)

Adult respondents highlighted additional technical barriers to notifying organisations of a death including needing a form of ID and dealing with digital footprints. Respondents spoke of the need to know many different passwords to access multiple online accounts and the difficulties finding these.

“There is a real practical difference when that’s all online, all the different passwords. And often if you are trying to deal with your loved one’s affairs, you just don’t know what they’ve got there, what accounts they have got, so there is a real new issue there.” – oral evidence

All these processes were more difficult for people for whom English is not a first language and among older people when the person who dies is the one who was responsible for financial and administrative matters.

Not all respondents were able to use the Tell Us Once service to notify a death to government organisations due to coronial processes, as Tell Us Once would not accept interim death certificates.

“Because his death needed to be open to the coroner, an interim death certificate was issued. Consequently, I could not use the ‘Tell us once’ service.”- Woman in her 40s whose husband died of pneumonia (England)

Even for those who used it, Tell Us Once was felt not to go far enough, and the burden on bereaved people to notify other private companies such as banks and building societies; energy, electricity and water providers; telephone and internet providers, TV license and social media sites remained a significant challenge.

Services including ‘Life Ledger’ and ‘Settld’ are working to streamline death administration and notification of private companies, though these were not highlighted by individual respondents which suggests awareness might be lower.

2.3 Coronial process

Respondents to both the adult and organisational calls for evidence emphasised various difficulties around the coronial process.

The process - which establishes the facts around a person’s death, including how they died - can be extremely slow and drawn out, but also unpredictable due to inconsistency and lack of information on the progress. Respondents found this uncertainty very draining.

“There is unpredictability and unevenness of the service as a whole. The unpredictability affects investigations, decisions about whether to have inquests, how quickly an email is replied to, whether you will get someone bureaucratic or empathetic on the phone. The experience of the service for bereaved families often hinges on the sensitivity and receptiveness of the individual coroner or coroner’s officer and they may be working under quite extreme pressure.” – organisational respondent

The pandemic restrictions exacerbated and added to the challenges experienced by people during the coronial process. Organisations described how the pandemic lengthened the already drawn-out process of inquests and investigations.

I have been waiting 18 months for an inquest date and unsure when it will take place. I think that’s pretty unacceptable.” – Woman in her 50s whose mother died of COVID-19 (England)

Those who had to contact and attend coroners’ hearings during the pandemic found this particularly difficult. Organisational respondents also described a range of difficulties for bereaved people relating to the introduction of virtual hearings - which replaced some in person hearings during the pandemic with some people struggling to access online inquests due to barriers related to access to technology, or digital literacy. Virtual hearings also meant many relatives had to ‘attend’ alone and unsupported in their own homes, or with children present (sometimes while giving evidence). Joining virtual inquests from home was also distressing for some because it brought the death into the home.

2.4 Legal processes

Individual respondents described a range of difficulties with the legal aspects of death administration.

There were many issues around probate and estate finalisation, including confusion as to whether people needed to apply for it; confusion about what was required; difficulty getting the necessary paperwork; the high costs of solicitor fees; and long delays.

“Paperwork is relentless and not everyone can afford a Solicitor to carry out tasks such as probate and estate finalising. It’s difficult to do on your own if you have no support from family.” – Woman in her 60s whose husband died of pneumonia (England)

“Filling out Probate forms with legal definitions that I couldn’t understand.” – Man in his 70s whose wife died of cancer (Wales)

“Probate has only just been settled after 18 months which has been stressful for my mum.” – Woman in her 40s whose father died of COVID-19 (England)

Some respondents also struggled with the complexity around taxable and non-taxable pensions, administration related to a deceased person’s business, and sorting out tax credits and other benefits.

There were additional legal difficulties for unmarried bereaved partners who are not treated as next of kin in the eyes of the law and were not entitled to their partner’s legacy.

“As we were not married, I mean nothing to anyone. Yet we have a kid together but no one cares.” – Woman in her 30s whose partner died of a heart attack (England)

“Law preventing legacy from going to long-term partner (and mother of children) since not married.” – Man in his 40s whose brother died of a heart attack (England)

Changes needed around death administration and practical tasks

A streamlined pathway

Respondents stressed the need for streamlining and simplification of processes following a death and access to a centralised resource to link bereaved people to all the practical and emotional support they may need.

“It would be good to make the administration systems better. Having to send copies of death certificates to multiple places and communicate with lots of different departments is a challenge that should be avoidable. I think it will also get harder with the next generation where lots of things are online.” – Woman in her 40s who whose father died of COVID-19 (England)

Both adult respondents to the consultation and organisations had many suggestions for ways that different processes could be improved to make them easier to navigate and less stressful.

Some respondents suggested that there should be a national bereavement route setting out what actions need to be taken after someone dies, summarised as an admin checklist or booklet made available to everyone. Guidance on such a route would have to be accessible, available both online and in print and appropriate for different audiences.

“Kingston Hospital has a hospital booklet on bereavement, ...of a local places of worship. In addition to that, it mentions things like coroner's, it mentions things like the cemetery office and the registry office and the information you need. So I think the first start would be a hospital booklet. Using technology today, it wouldn't be impossible for the NHS or the hospital to find a translated copy on the website electronically in different languages. So the first stop in a hospital is a bereavement booklet” – Participant at the inter-faith roundtable

Both adult and organisational respondents found Tell Us Once and similar services to be helpful, but felt that there was a need for one single service that covers all organisations. Organisational respondents suggested engaging with the Government Department of Business, Energy and Industrial Strategy (BEIS) to try to further fund and expand Tell Us Once – which currently allows people to report a death to most government organisations in one go - into the commercial sector.

“If there was truly 'one service' that dealt with all the different companies.” – Woman in her 40s whose mother died of aortic dissection (England)

“We have been talking to BEIS about that. Sadly they are not very interested at the moment...But I think there is something about joining that whole system together.” – Organisation's oral evidence

Some respondents also suggested that a bereavement coordinator or navigator role could be funded to support people through the administration process if they are struggling, suggesting that this could be linked in at the point of registration. Others suggested facilitating pathways directly from other administration points such as the Coroners' service into bereavement support, and where relevant, medical support.

“I think the introduction of named support personnel in these areas would help. Individuals who are knowledgeable about available resources. Having someone to talk with face to face is invaluable. It is difficult navigating the websites at times and can be confusing.” – Woman in her 50s whose husband died of cancer (England)

“Honestly a personal assistant who could just do all the phone calls for me and simplify - let me know what decisions needed to be made and then take everything else off my plate so I could process and move forward.” - Woman in her 30s whose father died of artery dissection (England)

One respondent suggested an online coordinator tool:

“It would have helped to have had a point of contact that you could enter the details of your circumstances and it provided advice. Like advise on all the action you need to take in a list form. a. Speak with the undertaker, b. Register death c. Find and claim the life insurance or prepaid funeral plan. d. Contact Creditors and Debtors” Man in his 70s whose wife died of cancer (Wales)

B. Improvements to death administration and practical tasks at different touchpoints

i. Advance planning

There was a general consensus across the evidence that more needs to be done to encourage all aspects of planning for the end of life and death in society.

“When loved ones are able to have conversations with the dying person and understand their preferences and wishes, this makes the time after a death and sorting the practical and administrative tasks, much easier. Advanced care planning can be done years in advance, but most people are unaware that these decisions can be revisited and changed throughout someone’s end of life journey. Early conversations about what needs to be done post-death can also help to alleviate anxiety. This means the time immediately leading up to a death can be used to spend quality time with the person and can be spent in a way which matters most to them” – Participant at Welsh roundtable

Respondents made a wide range of suggestions relating to both cultural change and system changes.

Such campaigns must be sensitive to communicating with different communities, and used to raise the profile of advance planning and the benefits of doing it. This should extend to awareness of unintended consequences of not planning, for example not having own bank account or not being on a tenancy agreement. The information should include topics such as funeral costs and financial support available, and how to set up power of attorney.

In addition to a public awareness campaign around advance planning, organisations suggested roles for other stakeholders. Some suggested that health and care staff have a role encouraging conversations in helping families understand what will happen at end of life and what processes will be needed and therefore need to be appropriately skilled. Respondents suggested that GP surgeries could hold workshops on the practical elements. Respondents also suggested that faith groups could play a role, receiving training on helping people make plans for the end of life and that that schools could play a role in hosting workshops and teaching children about advance planning.

Suggestions for increasing advance planning:

- Public awareness campaigns should encourage people to write wills and to have discussions about their funeral
- Governments, local authorities or other statutory bodies should introduce a data framework for monitoring uptake of advance planning.
- Governments, companies and other organisations should capitalise on key moments such as buying a house, having a baby – or be linked to routine admin e.g. registering at GP.
- Pension providers should include guidance on advance planning with communications about pensions, or on the new pensions dashboard.
- Employers could consider introducing a new opt-in national funeral planning contribution on payroll.

“Talking about death and dying in advance – not just after death – is critical. It can help someone to process grief if planning and conversations are had in advance, even if this is as informal as conversations about funeral music choices. Difficult decisions, for example those around place of death and funerals, can be eased if conversations have been had over what dying well looks like to people.” – organisational respondent

ii. Death registration

Adult and organisational respondents made several suggestions about death registration:

- **The online option** should be maintained post-pandemic, but in person alternatives should be offered too.
- The registration of deaths and births should be separated.
- Unmarried partners and parents should have the same rights in death registration as people who are married
- Registration should be used as a point for providing practical information and signposting people to support.

iii. Notifying organisations

Suggestions for Governments included conducting a review of death administration processes and expanding Tell us Once to cover the private sector, ensuring standardised bereavement journeys across companies.

Suggestions for the private sector included simplifying processes by only asking for necessary information and avoiding repetition; permitting the use of digital or photocopied death certificates as proof of identity – adopted by some organisations during the pandemic. Respondents suggested that social media organisations must review the process for closing or memorialising accounts as this was felt to be too burdensome currently.

Suggestions for staff included having a bereavement support team or representative in every organisation; training for customer service staff in bereavement awareness, and signposting bereaved customers to practical and emotional support; and training for people in roles such as mortgage advisors to help prepare people for bereavement.

“These companies should also have clear, consistent criteria and standards for dealing with bereaved customers, taking note of the FSA report into the vulnerability of customers, and ideally working to a common framework. While individual private companies do not have the same infrastructure as disparate government departments to work together, the business case for dealing with bereaved customers empathetically and consistently should be sufficient incentive.” – organisational respondent

iv. Coronial process

Various recommendations were made to improve directly improve families’ experiences. These included training for staff on communication and sensitivity so that the needs of bereaved people could be put at the heart of the service; accessible guidance and support being made available to families throughout the process including advocacy so they can actively take part in the process; more communication on the timescales of an inquest; and quicker inquests where possible.

“Someone to guide us through the inquest process. I felt very poorly informed despite attempts to seek out support and guidance. It was not readily available.” - Woman in her 30s whose father died in an accident (England)

In order to implement these recommendations, respondents highlighted the need for more funding so the service is less overstretched.

“The service should also have help: better funding so that it is less over-stretched, an improved environment to work in, more time, bereavement and communication skills put at its heart.” – organisational respondent

v. Legal processes

Specific recommendations around legal processes included:

- Ensuring unmarried cohabiting couples have the same legal rights as married couples.
- A public awareness raising campaign about dealing with estates.

- A national helpline for probate, wills and administering estates.
- Simplified language in forms, and improved guidance through any necessary legal terminology.

“Forms that are much simpler to understand and not suffused with legal language. I am intelligent and well educated but needed advice of an accountant (friend) to understand the probate pension questions.” – Woman in her 50s whose husband died of cancer (Wales)

Conclusions and recommendations to improve systems around death administration

Bereaved adults and young people currently face a significant administrative burden after a death, with little or no support around these processes. **For those with practical or administrative responsibilities after a death, 61% said they struggled with these tasks.** 2 in 5 respondents reported difficulty sorting through financial affairs and 1 in 5 had difficulties registering their loved one’s death or arranging the funeral with a further 1 in 10 reporting difficulties with other administrative tasks.

The qualitative evidence revealed that bereaved people face many different practical and emotional challenges at all stages of death administration. For these reasons, the Commission is calling for the following recommendations:

Recommendations:

- 1** The UK Government 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.

While this chapter has focussed on the processes of death administration, a large part of carrying out these tasks is contacting people in different roles within companies and organisations. The next chapter will explore bereaved people’s experiences of this.

5

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

“

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)

”

“

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

”

The previous chapter discussed the challenges bereaved people face in death administration of not knowing what to do and through the high number of organisations they need to contact in the process. When having to navigate these difficult tasks in very challenging times, the sensitivity and skill of public facing staff is crucial.

Unfortunately, the evidence shared with us shows huge variability in bereaved people's experiences of the organisations they came into contact with throughout this process.

This chapter explores experiences of the people whose job brings them into contact with bereaved people when their everyday professional activity might not be centered around bereavement.

Key findings:

Bereaved people reported a range of challenges in their communication with staff across the full range of organisations they needed to notify 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

While these challenges were exacerbated by restrictions to in-person services during the pandemic and a shift to remote working, in many ways the pandemic exposed pre-existing weaknesses in understanding and attitudes towards bereavement in society as a whole, including public facing organisations.

The first section of this chapter outlines examples of good practice; the second section explores barriers to support and the final section outlines the change needed and the Commission's recommendations.

What helped when interacting with organisations

Guidance

Where it was available, respondents hugely valued the practical guidance and advice they had received from organisations they had to contact.

When professionals had a wider understanding of bereavement and the things needed to be done after death, this was appreciated.

“Not knowing what to do next... The funeral director was my rock to guide me through the whole process.” – Woman in her 40s whose father died of cancer (England)

Compassionate communication

In addition to practical guidance and advice and echoing experiences of end-of-life care, respondents valued when the professionals they encountered communicated sensitively and compassionately. Some adult respondents highlighted specific examples of good communication they had received from banks, energy providers and funeral directors. These included staff members being attentive, listening well, offering face to face meetings, and offering a private space to discuss sensitive matters such as financial affairs.

“The Building Society in particular was very attentive.” – Woman in her 60s whose mother died of a stroke (England)

“The [energy company] man who actually listened when I eventually lost my rag with their terrible accounts” – Woman in her 60s whose husband died of a stroke (England)

“Being able to talk to someone in person and in private at the bank” – Woman in her 30s whose father died of sepsis (England)

Barriers to support

Unfortunately, not all respondents' experiences of professionals during their bereavement were positive; adult respondents reported various difficulties in their communications across a range of different organisations such as registrars, banks and energy suppliers, amongst others. These included acting with coldness, insensitivity, a failure to advise them accurately on bereavement processes, and ignorance and insensitivity to the needs of minoritised cultures and religions.

Coldness

Respondents consistently reported encountering coldness and distance from professionals throughout the processes of death administration such as, the coroner, customer service teams and call centres, which made already complex processes even more challenging.

“The emotional overwhelming feeling when having to deal with all the admin and people’s lack of care for your feelings when doing so.” – Woman aged 18-30 whose father died of a heart attack (England)

“Coldness in dealing with the coroner, lack of empathy, battling through formal processes” – Woman in her 40s whose niece died of suicide (England)

Impact of the pandemic

This sense of distance and coldness at a very raw and painful time was made worse during the pandemic by a lack of face-to-face contact with organisations in a shift to solely online and telephone communication such as video calls, email and phone calls. Respondents found this very distressing.

“More call centre operatives and a Zoom link to talk to someone face to face. The whole process was”

Insensitive behaviour and comments

Beyond the perceived coldness from staff, some respondents found professionals at different touchpoints to be actively insensitive, making inappropriate comments and asking inappropriate questions which respondents reported had been deeply hurtful. Examples included asking repeatedly to speak to the deceased, commenting on their age or the way they died, and conducting due processes in a dramatic way, or failing to provide privacy around sensitive matters or when respondents were clearly distressed. This caused respondents unnecessary additional upset.

“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 heart failure (England)

“When registering the death, the registrar asked extremely inappropriate questions & made statements such as - “he was so young” it was deeply upsetting.” – Woman in her 50s whose husband died of cancer (England)

“When I registered his death the clerk held up his passport and dramatically cut the corner off of it in a theatrical and unpleasant manner. She was very odd and I was thankful that my son was with me.” –

Woman in her 70s whose husband died of cancer (England)

“If a spouse contacts them regarding a bereavement please don’t ask to speak to the account holder if they are the one who has died. Yes this frequently happened.” – Woman in her 40s whose husband/partner died of a pulmonary embolism (Wales)

“Being in public upset while talking to people in authority.”- Woman in her 50s whose husband/partner died of a terminal illness (Wales)

Not understanding bereavement processes

In addition, and linked to the problems around communication, respondents reported that staff did not always understand their organisation’s bereavement processes and were not able to advise them promptly or accurately. This further eroded their trust and heightened feelings of distress.

“The bank staff not knowing the process so had to visit 3 different branches of Barclays and numerous calls to the call centre. We needed access to my dad’s bank account to pay for his funeral we were told we should go to any branch of Barclays with a copy of the will, the death certificate and our ID and the process would be sorted. The first branch said they had no appointments for 2 weeks, the 2nd branch said we needed to go to my dad’s branch (which had now closed). The 3rd branch were sympathetic and had to call the head office but were able to help us find the forms to sort the bank account. We had to wait 90 minutes in a branch while they checked what the process was” - Woman in her 50s whose father died of cancer (England)

“Several organisations sent inappropriate and inaccurate messages when changing bank accounts - this caused me additional upset and reduced my confidence in their abilities to safely organise my affairs.” – Woman in her 50s whose husband/partner died of cancer (England)

Respondents felt that taken together, all these issues indicated a wider underlying problem that, in general, public facing organisations were not currently well set up to support bereaved families.

“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 e.g. at the bank she couldn’t speak to someone in private” - Woman in her 30s whose father died of sepsis (England)

Insensitivity to minoritised religions and cultures

Beyond perceived general insensitivity and incompetence from professionals, respondents expressed particular difficulties from staff in relation to minoritised religious and cultural requirements. Examples given included bank staff not understanding the status of wakes in Jamaican funerals and staff across many organisations being insensitive and ignorant around Islamic rituals and requirements. This had significant impacts on being able to carry out the ceremonies and procedures required by their culture which was naturally very distressing.

“The branch were very unhelpful and refused to release funds to pay for the wake. We did not ask for the money to be transferred to us but paid direct to the venue and caterers. At the heart of this was a form of racism - my dad was Jamaican. Jamaican funerals are a celebration of the life of the person who died. The wake is as important as the church and burial.” - Woman in her 50s whose father died of cancer (England)

“Trying to arrange an Islamic funeral and finding a general lack of knowledge of our rituals and requirements within the personnel at the hospital. We also experienced a similar level of ignorance with airlines and other administrative functions.” - Woman in her 30s whose mother died of organ failure (England)

Change needed when interacting with organisations

Echoing the recommendation made in the previous chapter about training for professionals whose role brings them into contact with families before and during the death, many organisational respondents agreed with the suggestion of **mandatory training in bereavement awareness for** all staff coming into contact with bereaved people. This would include all those with a front facing role in public, private and third sector who deal with death administration, such as registrars, solicitors, those working in banks and building societies, energy and phone companies amongst others.

Training should include:

- Emotional intelligence and communication skills.
- Awareness of different religious and cultural practices and requirements.
- Equality and diversity.
- General awareness of all key areas of death administration.
- How to advise and support people with practical processes.
- What healthy grieving looks like at different ages, how to spot signs of trauma/ prolonged grief disorder.
- How to signpost or refer people for further support.
- Modules on specific forms of bereavement e.g. bereavement by suicide, pregnancy and child loss.

Conclusion and recommendations

This chapter has highlighted the added difficulties they face in contacting relevant organisations after a death.

Many respondents reported a lack of support and sensitivity from organisations whose job it is to complete necessary actions when someone dies and found that this made the administrative burden they faced yet more challenging and upsetting.

It is vital that bereaved people are better supported through these steps, and are treated compassionately, not just around the death but throughout their bereavement. The workforce also need to be trained to support people affected by more complex and traumatic bereavement, as well as bereavement in exceptional circumstances such as future pandemics, which is why we are calling for the below recommendation:

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.

This chapter and the previous chapter have discussed the practical tasks after a death. One of those not mentioned so far, however, is organising a funeral. While many people find the funeral itself to be highly valuable it comes with its own challenges and support needs: these are the subject of the next chapter.

6

I have access to an affordable and meaningful funeral

“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.

5-12 YEAR OLD

Being able to acknowledge a close person's death and celebrate their life appropriately and meaningfully are important aspects of 'good' or healthy grieving. Funerals and other forms of memorialization provide a safe space and opportunity for bereaved people to express their emotions and share their grief with others. People reflected with the commission on the value of having a meaningful funeral and some of the difficulties and barriers they faced when organising one.

Funerals can add to the already high administrative burden on bereaved people, and the financial pressures people face after a bereavement, discussed in other chapters. While some bereaved people have the practical and financial resources to have a fitting funeral, and access to culturally appropriate ceremonies, unfortunately many do not. This creates additional distress and can impact profoundly on experiences of grief.

The COVID-19 pandemic only exacerbated these difficulties as well as significantly disrupting ceremonies and celebrations of life. Many people were not able to attend a funeral at all, while others had to accept services which were very different from what they or their loved one would have desired.

Key findings:

- Respondents found having a funeral, and other forms of memorialisation to be very important to them and their experiences of grief
- One in five (22%) of adults responsible reported difficulties arranging the funeral.
- The qualitative evidence revealed that these challenges ranged across all areas including knowing what to do, accessing a religiously and culturally appropriate ceremony, and prohibitive costs
- COVID-19 pandemic restrictions profoundly disrupted grieving processes, with three quarters of those bereaved during the pandemic reporting disruptions to a funeral (76%)
- While secular and Christian ceremonies are often simpler to arrange, many religious and ethnic minority groups face considerable barriers to organising a meaningful funeral

- Respondents' suggestions for change included greater financial support to support with a funeral; regulation of the funeral industry; a different approach to restrictions in future pandemics; and better access to appropriate funerals for culturally minoritised communities

The first section of this chapter outlines some of the factors which can contribute to a positive funeral experience; the second section outlines the barriers and challenges some people face in organising a funeral, including disruption resulting from the COVID-19 pandemic restrictions and the final section explores evidence on change needed and sets out the Commission's recommendations.

What helped with accessing an affordable and meaningful funeral

Having a funeral

Respondents who had attended a funeral emphasised the value to them of being able to mark their loved one's death, and in some cases to be actively involved in the ritual, especially those who were bereaved during the pandemic at a time when there were restrictions on funerals. Some recognised that this had helped their grieving process.

"We were lucky in that we were able to have a funeral with good attendance. I had underestimated the significance of this to help with the grief process. I worry that those who were bereaved during higher restriction periods would not have had this and that must have been really difficult and may impact upon their grief process." - Woman in her 30s whose father died of internal bleeding (Wales)

"Although there were the official statements of restrictions on numbers allowed at the funeral and not allowing priest for Last Rites or hospital visitors... there were times when a nurse would kindly let a priest or visitor in and no one was turned away from a church funeral which was good to see." Man aged 18-30 whose father died of liver failure (England)

Amongst the respondents whose funerals were restricted due to pandemic restrictions, some described how they valued the opportunity to stream the funeral online so that they or others could attend when not otherwise possible.

"I could not go to the funeral - partly due to COVID-19 restrictions, and partly because of my health. A video link was provided to the funeral service, and was very helpful" Person in their 60s whose son and male partner died (Wales)

"Being able to livestream my baby's funeral was so impactful and really helped us feel more supported. My local church opened twice a week for private prayer and it gave me a safe space to grieve and a reason to leave the house." Woman in her 30s whose son and grandparent died (Wales)

"We were able to meet the [funeral director] face-to-face & that was very reassuring as was the option to have the service live streamed which helped with attendance in the context of the pandemic; the crematorium were also very kind with us making arrangements to scatter the ashes there". – Woman in her 40s whose father died of a stroke (Scotland)

Other forms of memorialisation

In addition to funerals, respondents mentioned the value of other forms of memorialization. They described how sharing stories, tributes, music, artwork and shared interests allowed a powerful, alternative form of expression and remembrance and provided a lasting bond with the person who died. Examples shared in the evidence included the National Day of Reflection, to remember all who die during the COVID-19 pandemic, and walls of remembrance.

"Common music and interests I shared with my father [helped]" (13-15 year old)

"People express themselves in many other ways ... some of the other initiatives that exist currently and memory stones and walls of remembrance." – Participant at Northern Ireland roundtable

"Other organisations have provided spaces where people can come together to share stories, do tributes, artwork, music etc" organisational response

Beyond having a funeral, respondents identified a number of key factors which supported them to have meaningful funerals and last rites including: advance planning, financial support, and using culturally specific providers.

Advance planning

Reflecting what we heard in previous chapter, people whose loved one had made plans for their funeral such as instructions about how the ceremony should be conducted found this helpful when it came to organising a meaningful funeral. Some respondents had also benefited when their relative had saved money for the funeral, sometimes in a special funeral fund as this eased the financial burden.

“We were fortunate that my mother had a funeral plan in place, together with instructions as to how her funeral was to be conducted” - Woman in her 60s whose mother died of a terminal illness (England)

Culturally specific suppliers

It is vital for a meaningful funeral, that bereaved people are able to honour their loved one’s cultural and religious values and beliefs. The evidence the commission received revealed that many funeral directors and other suppliers in the UK unfortunately only cater to White British, Christian and secular traditions. In this context, the oral evidence highlighted the value of a directory of end-of-life services with one example shared from African and Caribbean communities:

“Just to quickly say two other bits of good practice is that they have now started a directory of end-of-life services for people from the African and Caribbean communities. So, you can find funeral directors, you can find caterers, it is an online directory.” – Oral evidence

Financial support

In light of the high costs of a funeral, respondents in both the individual and organisational evidence also highlighted the benefit of financial support they had received towards the funeral. For some, this support came from relatives and friends, while others received support from governments and other organisations. Bereaved parents mentioned the value of the government support towards funeral costs for children under 18.

“The government rule that allows free funerals for children was a blessing.” - Man in his 30s whose child died of a terminal illness (England)

One example shared in the oral evidence highlighted support from the Majonzi fund through The Ubele Initiative which provides grants to families to enable them to have a memorial.

Challenges in accessing an affordable and meaningful funeral

Organising the funeral

Individuals described the administrative burden and stress related to organising the funeral, on top of other death administration as highlighted in chapter five, particularly when there was no support from family or they had to organise travel especially for this event.

RW

*Arranging a funeral when traumatised is ridiculously hard and I don't know why our culture expects it of someone in trauma.”
– Woman in her 40s whose husband died from cancer (England)*

“A lot needs to be done in a very short space of time after death and I did not feel in the right frame of mind to arrange the funeral.” Man in his 50s whose wife and father-in-law died (England)

“
Arranging a funeral when
traumatised is ridiculously hard
and I don't know why our culture
expects it of someone in trauma.
”

**WOMAN WHOSE HUSBAND
DIED FROM CANCER**

This was made harder with the difficulty of finding information on the process of organising a funeral adding to an already difficult event. When the relative had not left a will, it was unclear what type of funeral they would have wanted. Some respondents described how this had led to disagreements in the family.

“Knowing how to plan a funeral is also an issue that we see a lot. The different administrative tasks, what order things happen in, what all the different terminology means, what the various bits of paperwork are for. Lots of people will not organise a funeral hopefully, lots of times, and so it’s something that people often don’t have experience” – Oral evidence

“No will being left disagreements in the family re funeral arrangements” - Woman in her 50s whose uncle died of COVID-19 (England)

On top of existing difficulties, respondents bereaved during the pandemic mentioned how the constantly changing rules and restrictions made it particularly hard to plan. Both individuals and organisations described uncertainty over the long-term consequences of these restrictions, and whether planned memorials could take place and whether family needs would be met for these.

Delays to funerals

The evidence highlighted that families can wait a long time for a funeral because councils limit the number of burials per day. Delays to funerals can be particularly upsetting for those bereaved families whose faith requires a swift burial, such as the Jewish principle of honoring the dead (k’vod hamet) and the Muslim custom of burying the dead promptly.

Lack of religious and cultural sensitivity

Respondents to the survey reported difficulties in accessing culturally specific packages when it came to organising their funeral, and accessing funeral directors who can conduct funerals for certain religions, for example conducting Islamic funerals.

“Many organisations do not have culturally appropriate bereavement services because they do not understand the differences in cultures, for example, some of the funeral directors, their service is prescriptive, this is what you get, this is how the service happens. I know first-hand that there has been an instance where the complaint is, “Why do black people have to take so long with their funerals, 20 minutes is what you get, why do you need half a day?” type of thing. Also, for those of us who are in particular professions, the service we get is quite inadequate” oral evidence

“Trying to arrange an Islamic funeral and finding a general lack of knowledge of our rituals and requirements within the personnel at the hospital.” - Woman in her 30s whose mother died of multiple organ failure (England)

“[A challenge was] finding a funeral director who could help with a Muslim funeral.” - Woman in her 30s whose mother died of multiple organ failure (England)

The oral evidence highlighted prejudice and reluctance from some funeral directors and crematoria to support the large funerals that are traditional for gypsy and traveller communities as well as challenges with organising funerals at a distance to honour burial wishes. There were particular issues accessing churches, halls of praise, centres and clubs for funerals and other rituals (for example Nine-Nights) in cities with restricted streets, with families reporting experiences of receiving parking tickets despite having a ‘funeral in progress’ sign in the window that is allowed under by-laws. The oral evidence also highlighted problems caused by loss of community centres that host these type of functions, and potential tensions caused by hosting these events in private homes again. Some funeral directors had prevented families from the tradition of resting the coffin in a caravan before the funeral, resulting in distress.

Nine-Nights is a tradition practiced in the Caribbean. It is an extended wake that lasts for several days, with roots in African religious tradition. During this time, family, friends and family come together in the home of the deceased. They share their memories as well as food, drink and music together.

Oral evidence participants reported that some Council site managers and police also fail to understand traditions around wakes and anniversaries which can involve whole communities and last several days.

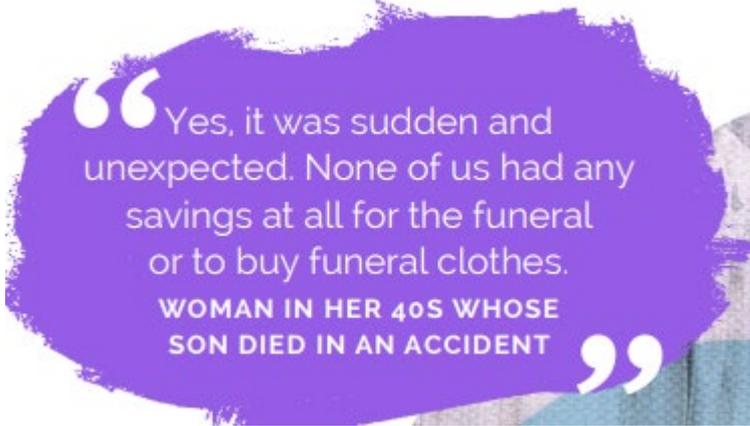
Costs

Despite there being some, limited financial support available, survey respondents highlighted issues around the high cost of funerals, cremation and burials, particularly for those in poverty, and those who experienced sudden, unexpected deaths without having savings.

My wife's death at 36 years old was unexpected and we didn't have life insurance etc. so I had to rely on family to pay for the funeral. If I didn't have this support, I would have had to go into debt." Man in his 30s whose wife died of a stroke (England)

Respondents described the emotional toll of struggling to pay, and pressure to meet societal expectations for a 'proper funeral', leading to extreme worry, and some resorted to borrowing money or using credit cards.

"We already suffered massive trauma for our loss, my husband got COVID-19 because he went to work. The pain of his death was torture enough without the added worry of how to cover his funeral costs." - Woman in her 30s whose husband died of COVID-19 (England)



“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”

"Many of the people we support are overcome with worry about how they will pay the funeral bill - a recent client of mine explained how she couldn't sleep because of the worry it was causing her, and when she did manage to, she would wake up sweating from the fear of how she would pay the bill. One client didn't feel she had the right to visit her husband's grave because she had not finished paying the bill." – organisational respondent

"I had to borrow the money from friends to pay for the funeral directors and cremation costs which at the cheapest rates was over £3,000. I couldn't afford burial which was over £6,000." - Man aged 18-30 whose father and friend both died (England)

Difficulty accessing finances

Respondents described a range of barriers to accessing financial support for the funeral. Those waiting for insurance payments highlighted the uncertainty around when these would come through.

Organisations stressed that it was difficult for those with poor credit ratings to access funds and payment schemes. And due to restrictions on benevolent funds for covering funeral costs, there was an increasing reliance on crowdfunding such as 'go fund me.'

Others expressed a sense of desperation that only people on certain benefits were eligible for funeral support payments, leaving many people who needed this support ineligible.

“I have no idea when insurance payments will come through and without support of family and friends I would be going into debt to cover funeral costs” - Woman in her 30s whose husband died of a cardiac arrest (England)

“We also did not get any help with his funeral - financial, because he was 18. If he was 17 I could have claimed for financial assistance as a single Mum” - Woman in her 40s whose son died of cancer (England)

“My brother had no insurance etc and was in receipt of benefits, trying to access financial help for his funeral was a nightmare! You have to be in receipt of benefits yourself to access a funeral payment, else the family are expected to pay for it!? How? If your money is tight, where do you get up to £5000 from to pay for a funeral!” - Woman in her 50s whose brother died of COVID-19 (England)

Respondents reported that the process to access the Funeral Expenses Payment is complex and that they do not know how much they will get when applying, resulting in difficulties making decisions about the funeral. Organisations also reported the slow processing of claims from criminal injuries compensation for homicide cases.

“Claimed a grant to cover funeral costs but it was very time consuming and slow.” - Woman in her 60s whose husband died of COVID-19 (England)

These challenges were more acute for families whose faith requires rapid burial or cremation including Sikhs, Muslims, Hindus and Jews.

“For Muslim burial it is done virtually straight away and without knowing where funeral costs will come from to pay.” - Man in his 40s whose mother died of old age (England)

In addition to their inaccessibility, both organisations and individual respondents highlighted the inadequacy of the Funeral Expenses/Support Payment – suggesting that it typically covers only 40-50% of the average funeral cost, meaning even those who received this support struggled with the costs not covered by this.

DWP paid for half of funeral, but I had to borrow the rest” – Woman in her 50s whose husband died of a terminal illness (Wales)

“Going by the most recent data, the average funeral expenses payment covers, the award only covers forty-one per cent of the average cost of a simple funeral, and the funeral support payment in Scotland on average covers only fifty per cent. And the main problem of those payments is the capped portion of the payment. So that was frozen at seven hundred pounds for seventeen years and was increased by just three hundred pounds last year. In Scotland it’s now one thousand and ten pounds, because it’s linked to inflation in Scotland but it’s not in the rest of the UK. And that is essentially intended to cover everything and all the cremation, all the burial fee and the doctor’s fee, so all the funeral director’s fees, the coffin, the transport for the deceased, the officiate, all of that. And a thousand pounds is very, very rarely enough, so it can leave the bereavement with a significant shortfall that they are unable to pay.” – Organisation’s oral evidence

Organisations emphasised that the underlying cause of these high costs was the lack of regulation of the funeral industry with no minimum standards on either conduct or regulation of costs.

Inadequacy of Public Health Funerals

Unfortunately, for those unable to pay for or organise a funeral for the person who has died, organisations highlighted local authority failings around public health funerals. They described increased stigma and hostility towards people who need to use these as well as less access to public health funerals.

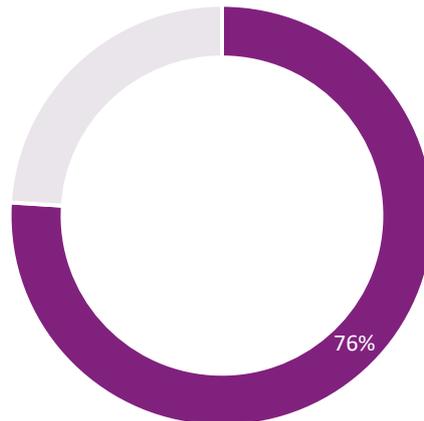
Public health funerals are provided by local authorities for people who have died and have no next of kin, or whose next of kin, relatives or friends are unable or unwilling to make the necessary arrangements for a funeral.

There is a statutory duty on local authorities to arrange for a burial or cremation where no suitable alternative arrangements are being made. However, the Act does not define how local authorities should carry out this duty – meaning there is considerable flexibility in how these funerals are delivered.

“It has become more difficult to access public health funerals ... and I appreciate that it is entirely due to austerity and financial pressures in local authorities and hospitals .But there is often a very antagonistic attitude to people who are already deeply distressed at not being able to provide a funeral for a loved one, often older people with an adult child, which they are devastated by and they get real pressure.” Oral evidence

Impact of COVID-19 pandemic restrictions

Proportion of respondents bereaved during the pandemic who said they were not able to have the funeral they wanted



Over three quarters of respondents to the commission’s survey bereaved during the pandemic (76%) said they were not able to have the funeral they wanted due to COVID-19 pandemic restrictions.

Disruption to funerals resulting from lockdown restrictions such as delays, restrictions in numbers, and social distancing measures had a profound impact on the grieving process and celebration of life.

“We couldn't have a funeral for him. He was only 29 and he was cremated immediately due to COVID-19. That was hard.” - Woman in her 30s whose cousin died of an overdose (England)

Not being able to attend

Tight restrictions on attendance at religious services; outlawing of other collective rituals such as wakes, shivas, collective recitations at home, Nine Nights and viewing and embalming of bodies, as well as travel restrictions during the COVID-19-10 pandemic, all meant some people were unable to attend funerals. Some organisations suggested that children and young people had been particularly impacted by the restrictions on numbers, expressing dismay that under 12 year olds counted towards overall numbers in this context when they did not in other social contexts.

Individual and organisational respondents highlighted high levels of distress around being unable to attend a funeral, and respondents spoke of how this made it impossible to grieve properly.

“It’s extremely difficult to move forward as all the usual processes of grief did not happen. Not one single person at the funeral so it felt like I’d just watched an episode of EastEnders or something. No sitting with family and friends afterwards (wake)” – Woman in her 30s whose mother died of COVID-19 (England)

“We have been surprised that in a social situation, children under 12 were not counted as ‘numbers’ but when it came to funerals, they were considered within the numbers and it did not allow those who were bereaved to grieve.” – Children’s bereavement support organisation

The evidence also highlighted difficulties fulfilling the person’s wishes to repatriate their and challenges arranging overseas families to attend funerals in the UK or for UK residents to attend funerals overseas.

"I also have to return my mother's ashes back to India as i did with my father, there is no consideration for cultural ceremonies and processes we have to complete"- Man in his 50s whose mother and father both died (England)

Limited numbers

Even for those who were able to be there personally, individuals reported that it was deeply upsetting that restricted attendance did not reflect the deceased's impact across their family, friends and wider community.

The disruption of rituals and opportunities to grieve together such as at funerals had left people lonely and isolated, with some individuals reporting the distress at having to attend a funeral alone or without their immediate family. Strained family relationships caused by restrictions to numbers.

"My wife's family live over 200 miles away and were not allowed to travel because of COVID-19 restrictions and as I have no family I was on my own on the day of the funeral I had to sit on my own in church as I was not allowed in to the crematorium because it was a simple funeral" - Man in his 70s whose wife died of COPD and heart failure (England)

"Funeral with only 5 people present." – Woman in her 60s whose mother-in-law died of COVID-19

I wasn't able to have my closest family or adult children with me. I had to travel alone to my mums funeral." - Woman in her 50s whose mother died of a haemorrhage (England)

"The restricted protocols at funerals led to it being a challenging experience for myself and the family." - Man in his 50s whose father died of COVID-19 (England)

The restrictions also meant some people were unable to give people the send-off that they had wished or was culturally expected. This left a painful legacy and was particularly felt by communities with a tradition or expectation of large gatherings.

“

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

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"People are carrying around emotional baggage right now because of not being able to pay their respects, not being able, the nine nights ritual. Different Caribbean islands have different rituals but it's all about the same thing, it's about that coming together of family and friends who might not have seen each other for a long time but they have something in common; this person who has passed on. You get to hear, as he said, about their life that you didn't know about. There is a common bond that strengthens people in dealing with their grief." – Oral evidence

"People of different ethnic and faith groups grieve differently and have a different sense of what will bring closure. For example, to deny an Afro-Caribbean family the opportunity to fill in their loved one's grave simply because of regulations or time constraints can leave that family feeling that their loved-one was not given a proper burial and exacerbate their grief. This is a common problem I have often encountered. There is a

wealth of cultural understanding in different ethnic and faith groups within the community.” – organisational respondent

Change needed to improve access to an affordable and meaningful funeral

Respondents made recommendations around improving the affordability of funerals, including access to financial support; cultural sensitivity and future mass bereavement events.

Practical guidance

Respondents emphasised the need for more practical guidance including better information on funeral options such as a Council funeral advisory service. This should be available in advance of when people need it to encourage everyone to have a funeral plan. Examples given included in a council tax statement or in discussions towards the end of life when a death is expected.

Some respondents felt this could happen even earlier, arguing that secondary schools could play a role in educating pupils about funerals and funeral options.

Other respondents felt that funeral directors could play a greater role in signposting and providing information on all practical processes beyond the funeral.

“I think talking openly about what you want when we die is really important. For example, to be buried or cremated, having a will, if you are cremated where you want your ashes scattered. We didn’t know any of this information for my cousin so these decisions were tough.” - Woman in her 30s whose cousin died of an overdose (England)

Improved financial assistance

Organisations and individuals both argued that funeral poverty needs to be recognised and addressed with various specific recommendations made in relation to financial support.

“There needs to be financial support for people like me who work full time, don't earn a lot of money and are not eligible for benefits. You don't expect to lose someone, and you don't prepare yourself financially for something like this at the age of 23. But as a responsible adult I had to deal with this, I had to set up a fundraising page for the community to help me pay for my mothers funeral, this was very helpful but it was extremely embarrassing for me to have to do this.” - Woman under 30 whose mother and grandmother both died (England)

Recognising that bereavement benefits aimed at providing financial relief (such as Funeral Support/Expenses Payments) do not actually cover funeral costs, they argued that these need to be increased to meet the real expense of a funeral. Some argued they should also be extended to excluded groups such as students.

In addition to increasing the above support, respondents argued that Funeral Expenses/Support Payment must be made available earlier for those whose religions require quick burial.

Regulation of the funeral industry

There was evidence presented that funeral poverty is in large part a result of an unregulated funeral industry. With this in mind, organisations argued for greater regulation of the industry with suggestions including introducing regulations to limit inappropriate upselling and discriminatory payment terms.

While survey respondents acknowledged that the Competition and Market’s Authority price comparison has increased transparency on funeral costs (by a requirement for services to publish a standardised price list online and in offices) it was felt that there were still problems with compliance concerning some funeral directors, and also a lack of detail on what standardised prices entailed.

Beyond regulation of prices, some respondents argued that funeral directors should be regulated also in terms of the care they give to bereaved people, for example, by introducing mandatory training in bereavement support.

“It occurred to me that funeral celebrants could do so much more to help if they were trained in bereavement care.” – organisational respondent

Culturally sensitive services

Respondents felt there is a need to ensure that out of hours systems are in place to enable the rapid processing of death paperwork necessary for burials to happen quickly, which is important for some communities, including many people of Jewish and Muslim faith. These are available in some localities but not nationally across all parts of the UK.

Respondents also argued that funeral directors must focus on developing standards of care and improving their understanding of the needs of currently minoritized and underserved communities’, for example of washing and dressing rituals, and communication with families, so they can better express what they want.

Some felt the best way to meet people’s needs was through training for funeral directors and celebrants on different communities’ funeral and burial practices, while other respondents suggested the introduction of faith specific funeral directors to represent the full range of religious views in the UK.

Improvements to public health funerals

Recognising that not all bereaved people are able to organise a funeral, and in light of the current inconsistency in public health funerals (highlighted earlier in this chapter) organisations suggested that statutory minimum standards for public health funerals must be introduced to ensure that experiences of a public health funeral are not a postcode lottery.

Maintaining new funeral access options

While the pandemic in many ways impacted on funerals negatively, some respondents felt that adaptations and innovations introduced in this period should be maintained as an option going forward, as they were more accessible for some people. These included virtual meetings to arrange funerals and the option of livestreamed funerals, which are both useful when relatives living overseas want to attend. Respondents felt that livestreaming for funerals and burials should come at no extra cost.

Preparation for future mass bereavement events

Respondents felt that lessons should be learned, and steps should be taken to improve funerals and burials in future mass bereavement events. Many people felt that more careful consideration should be given before restrictions are introduced on funerals in future, recognising the profoundly negative impact on experiences of grieving. Some respondents suggested exploring the possibility of allowing outdoor services during a future pandemic or mandatory testing for all attendees.

Additionally, one respondent suggested that Councils should be able to take over green spaces for burial in a future mass bereavement events.

“I think the COVID-19 rules should allow for support in these situations also a funeral is the last chance to say goodbye. This could have been organised better surely we could have had outside services with social distancing. Or lateral flow tests before attending a funeral.” – Man aged 18-30 whose friend died by homicide (England)

Conclusion and recommendations

Funerals can play a critical role in bereavement as a chance to publicly acknowledge a death, collectively express grief and celebrate someone’s life.

However, more support is needed to ensure that everyone can access and afford a meaningful funeral – with more than one in five (22%) adults who responded to our survey reported difficulties arranging a funeral.

It is also crucial that people are better supported in their bereavement in future pandemics, and that wellbeing considerations are more carefully balanced with infection control.

That is why we are calling for the following changes:

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)

While this chapter has exposed some of the financial challenges faced by bereaved people around dealing with funeral costs, the next chapter explores the financial challenges people may experience after a bereavement.

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

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“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

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Bereavement can often be a trigger into 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 particularly the case for bereaved partners or spouses and any dependents in the household, where the bereavement commonly results in a loss of household income and can even lead to the bereaved person or family losing their home. Such pressures add significantly to the emotional stress and grief of the family, including children and young people in the household who are often aware of their family's financial difficulties.

In this chapter we present the main challenges identified in the evidence received by the commission in relation to the financial impacts of bereavement, barriers to accessing financial support and housing insecurity. We then summarise the suggestions made by participants for improving financial support and housing protection before presenting the Commission's recommendations for change.

Key findings:

- Bereaved people, in particular partners/spouses, commonly experience financial difficulties due to reduced household income (e.g. loss of wages, benefits and pension-based income).
- Navigating the financial-support and benefits system to access the 'right' entitlements is complex and difficult to manage at an already stressful time.
- Some forms of financial support are only available for bereaved spouses and excludes unmarried partners (including those with children) as well as excluding some other groups
- The current amount and duration of financial support following bereavement is inadequate for many families, especially those with children.

- Kinship carers are denied statutory support despite often facing significant practical and financial challenges when they take on responsibility for the bereaved child/children following the death of their parent(s)/guardian(s).
- Due to financial hardship and the nature of some tenancy agreements surviving family members can also find themselves having to move house, or in some cases facing homelessness, soon after the death.

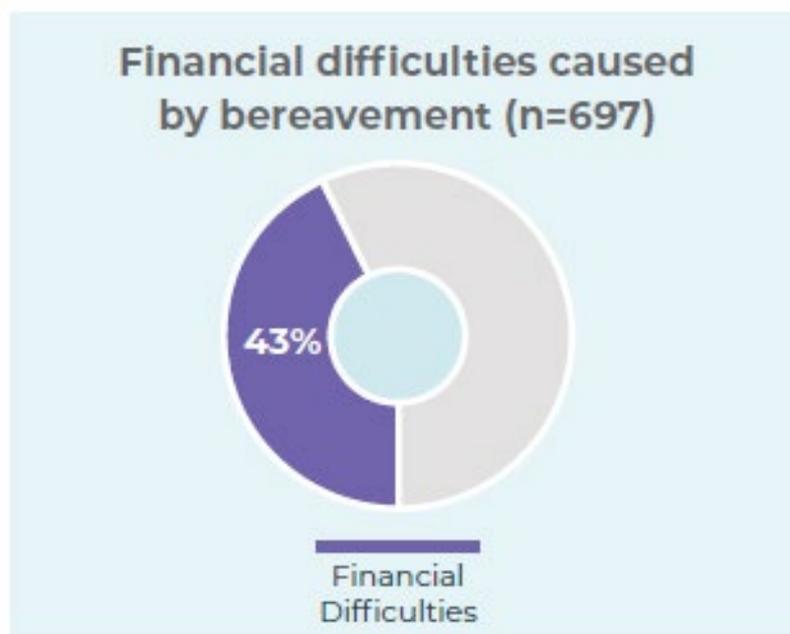
Participant suggestions for what would help included:

- Better information and advice being provided on financial-support
- A welfare system that is easier to navigate so people receive the money they are entitled to
- Greater financial and practical support for bereaved partners/spouses and parents
- Better statutory support for young carers when a parent is terminally ill, extending into bereavement and swift reassessment of family support needs when a disabled child is bereaved of a parent or carer
- Greater protection for surviving family members living in local authority housing

Financial challenges and difficulties

Financial impacts of bereavement and accessing support

Bereaved participants gave examples of some the financial difficulties that they faced following the death. Most commonly these financial problems impacted those who had been bereaved of a partner or spouse and the related reduction in household income. However, other bereaved family members also described the financial difficulties they experienced when having to cover the costs of funerals and other death-related administrative costs. Of the bereaved adults who answered a question on financial difficulties due to bereavement, 43% reported financial difficulties, and this increased to 50% for those who experienced the death of spouses/partners. This increase was substantial enough to be statistically significant¹¹.



Organisations also highlighted how during the pandemic, families were more likely to struggle with issues such as redundancy, overwork, furlough and other practical and financial challenges. The sudden costs of funerals are also more challenging given the pandemic's overall impact on household finances.

¹¹ $\chi^2(1) = 33.32, p < .001, \phi_c = .21$

“Paying For everything was challenging. Trying to claim money owed to mum back into estate is challenging too” - Woman in her 40s whose mother died of COVID-19 (England)

More detailed evidence on financial challenges and welfare support following bereavement was given in the oral evidence session which focused on the financial impact and death administration. In this session expert-participants explained how surviving partners can be left by themselves to pay mortgage, rent, household bills and childcare costs.

In addition to reduced income caused by the loss of wage-based earnings of the deceased (and potentially surviving partner if they are unable to return to work), bereaved families in receipt of welfare payments can also lose out on this financial support. For example, if the deceased was in receipt of employment support allowance or disability living allowance this would automatically stop upon their death, as would the carers allowance that the surviving partner may have been claiming. Loss of personal tax allowance for the deceased person’s pension also results in a reduced household income.

“When you had two people paying a mortgage, if you had no protection on that mortgage, you are still left with the full amount. Your oil bill isn’t going to go down, you are still going to have to have the heating on the same, your electric may go down a little bit but not a lot. If you have children, you know, your income isn’t going to, you know, if you are reliant on benefits you are going to be affected by that as well. Because your partner’s income, you know, if it had been disability benefits you maybe were a carer, you are looking at quite a drastic cut in income for the family.” – (Oral evidence, financial impact and death administration)

“The main financial challenges affecting people following bereavement a lot of it is down to the reduced household income. If the household was on benefits and it was a couple’s claim, you are basically looking at quite a drop in income. There is also the worry and the grief which can affect the remaining partner and affect their ability to work and then further affect the household income.” – (Oral evidence, financial impact and death administration)

The complexity of navigating and potentially switching to new benefits following the death was also noted, as was the lack of awareness and knowledge of these systems and entitlements. The fact that Universal Credit can’t be backdated for bereavement also means that the bereaved person needs to switch immediately following the death to avoid losing out. These complexities and associated insecurities are particularly challenging in families where the deceased dealt with household finances or for people not fluent in English.

Bereavement Support Payment is a form of financial support paid to bereaved partners under State Pension age whose husband, wife or civil partner died. It is currently only payable to married partners and only to those whose partner made sufficient contributions to National Insurance – with the exception of when the partner died from an accident or disease caused by work.

In 2018 the Supreme Court ruled that the exclusion of unmarried partners with dependent children from eligibility for the payment was not compatible with the European Convention on Human Rights (ECHR) and the government agreed to change this, but the law has still not yet been changed.

Following a successful legal challenge, it is expected that the Bereavement Support Payment – a key form of financial support following bereavement - will soon be extended to include unmarried bereaved parents. However, progress on this has been slow, and the fact that unmarried cohabiting partners are not currently eligible for the Bereavement Support Payment was seen as unfair and outdated. For some, it meant they had serious concerns as to how they would cope financially.

*“No bereavement support allowance as not married even though two children one with learning disabilities.”
– Man in his 30s whose wife died of COVID-19 (England)*

*“Not married so entitled to f*** all help from the government, yet we have kid together. No benefits possible as my savings slightly over threshold. No clue how financially will manage.” - Woman in her 30s whose husband died of a cardiac arrest (England)*

“

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

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In the oral evidence session on financial impact, it was also explained how bereaved spouses can be ineligible if the deceased hasn't paid enough national insurance contributions, such as those with a disability or young widows. For those who were eligible, the Bereavement Support Payment was also felt to end too early, at 18 months, and to provide a much smaller amount than the former 'Widows Allowance'.

“Families don't stop grieving after 18 months.” Woman in her 40s whose husband died by suicide (England)

“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 in her 30s whose husband died of a heart condition (Northern Ireland)

Currently, if a kinship carer takes on the care of a child in an emergency situation (including following COVID-19 deaths), the local authority refuse to help on the grounds that this is a private arrangement. This was also a concern given the particular financial and practical challenges experienced by kinship carers in these situations.

Housing insecurity

The financial hardship caused by bereavement can even mean that people lose their home, when the drop in household income means that they can no longer afford rent or mortgage payments. Bereaved people who shared evidence with the commission described how being forced to leave their home, with all its memories, compounded their feelings of distress and trauma, especially so soon after the death.

“I would not have been able to afford rent, multiple trips to the hospital (with parking) if work had not paid me. I had to move back with my parents after he died as I couldn't afford the rent on my own but having to move straight away was quite traumatic.” – Woman in her 30s whose husband/partner died of cancer (England)

In the oral evidence session further problems with housing- eviction were discussed. It was noted how people in local authority housing can be asked to move out if they are not on the tenancy agreement, and may be required to move to a smaller property.

It was also noted that private landlords sometimes evict families if the main earner dies to avoid dealing with the housing support and benefits system. Surviving family members then face further challenges in raising sufficient funds to cover security deposits and advance rent-payments on a new property, at a time when they have likely also had to pay expensive funeral or other administrative costs associated with the death.

These insecurities can be exacerbated by reductions in the amount of housing benefit paid following the death. Recent changes to government support for mortgage payments (so that these are now only available as a loan to those on qualifying benefits) can also create difficulties for bereaved people struggling with mortgage costs.

“I had a friend who died of COVID-19 at the beginning of the year and she lived in local authority housing with her children. And once she died the Council then went to reclaim the house. So her three children were then put into, they had to leave the family home that they had lived in all their lives, and rather than leave the three children in the house, they then put the three of them into three separate temporary accommodations. And it left the children completely, I mean they were lucky that the Council actually gave them somewhere to live, even though it wasn't suitable. But because they weren't on the tenancy, and this is what happens if a parent dies and you are not on the tenancy or the rental agreement, then you are evicted. (Oral evidence, financial impact and death administration)

“We have seen people use their rent payments to pay towards funeral costs. You know, a client of ours who had (...) children under eighteen, used her rent and food money to pay the thousand pound deposit for the funeral director. And when we started working with her several months after the funeral, she was being evicted. So I think there are real issues there certainly. (Oral evidence, financial impact and death administration)

In the round table session with faith leaders, examples were also given of bereaved caregivers being made homeless following the death of the parent that they were living with and caring for, due to the estate and family home being left to, and then sold by other family members.

Change needed to improve financial challenges and difficulties

Within the evidence a number of different suggestions were made by participants to improve the financial support available to bereaved people, with a need for further research into the financial impacts of bereavement also identified.

Information and education on financial-support and preparedness

Respondents felt that information about welfare benefits and pensions should be provided to bereaved people following a death, and financial advice should be made more widely available to bereaved people. For example, older people need to be informed about Pension Credit – since some will become eligible for this benefit when their partner dies.

Respondents also felt there should be better education to improve financial preparedness for bereavement, including at schools and through training for financial advisors

“Along the lines of education, reference, mortgages and life insurance given at schools. And better advice and training for the mortgage advisors so that they give proper advice rather than, you know, in some cases it seems that they are just given advice that will make them the most money. I think people need to be aware how good critical illness insurance, terminal life insurance are and that it is worth considering investing in those. Plus pensions and stuff like that as well”. (Oral evidence, financial impact and death administration)

An easier to navigate welfare system

Respondents felt that processes for claiming financial support were overly complicated, and need to be more transparent and simpler. For example the DWP should investigate why eligible people are not receiving Pension Credit and act to improve this.

Better support systems could help make access easier. In particular, the DWP website and bereavement helpline needs to provide a more comprehensive and 'joined-up' service to enable people to access appropriate financial support.

“So there could be much more done I think to sort of handhold people over. Okay it's the end of HMRC's responsibility for paying benefits to that person, but they need some sort of guidance to get into the new system, particularly dealing with it at such a difficult time”. (Oral evidence, financial impact and death administration)

The “Bereavement Support Payment” should be improved

Recognising current inadequacies with the Bereavement Support Payment, respondents felt this should be extended to unmarried cohabiting couples, especially those with children, progressing the previous agreement by the government to change the legislation following the Supreme Court verdict that it is incompatible with the European Convention on Human Rights (ECHR). The Bereavement Support Payment should also be extended beyond 18 months and recipients given the option to receive it in a lump sum.

Conclusion and Recommendations

The evidence presented in this chapter has further highlighted some of the difficult financial and material conditions experienced by bereaved individuals and families, including the complexities and challenges involved in accessing the ‘right’ benefits and the financial support to which they may (or may not) be entitled.

These stressful experiences compound the trauma and emotional and psychological distress associated with their grief and bereavement. Adequate financial-support, easy to navigate systems, and greater protection for those at risk of eviction is needed to mitigate the hardship suffered by so many bereaved people across the UK.

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 people will also need more formal emotional and/or psychological support to cope with a bereavement, whether from a peer support group, a volunteer or a professional therapist.

Key findings:

Those we heard from who received formal emotional support following a bereavement generally found it helped in providing a safe non-judgmental space to discuss their feelings and process their grief, and an opportunity to learn some coping strategies to move forward in life and in their grief.

However, individuals and organisations identified a range of barriers to accessing appropriate support:

- Stigma
- Lack of awareness of own needs
- Lack of availability of support
- Lack of support appropriate to individual and group needs (including age, ethnicity, religion, type of death and other underserved groups)
- Support not being available at the right time
- Support being insufficient in duration

Organisations also identified a wide range of underpinning issues affecting access to services including:

- Squeezing of services from both sides in terms of increased demand and decreased funding
- Lack of statutory funding for bereavement services which provide emotional support
- Inconsistent third sector and local authority grant funding impacting investment in and sustainability of services, and leading to a postcode lottery of emotional support being available

- Lack of appropriate training to emotionally supporting specific groups
- Lack of locally available data on both support need and service provision
- Insufficient monitoring and evaluation
- Not enough collaboration at a local or national level between voluntary and statutory services, at a local or national level

This chapter is structured into three parts. First, we explore access to formal emotional and psychological support following a bereavement including what helps, barriers to access and suggestions for change. Second, we consider how the needs of underserved groups can be met, taking an in-depth look at the challenges, needs and barriers to support experienced by underserved groups. These groups included racially minoritized communities, people experiencing homelessness, people with learning disabilities, LGBTQ+, and people in prisons. Finally, we move on to what is needed to deliver optimal and appropriate support which meets the needs of local and national populations, exploring the wider challenges faced by the bereavement sector in delivering effective and responsive services.

Access to formal emotional and psychological support following a bereavement

What helps

Respondents reported mixed experiences of both accessing and receiving formal emotional support services. From the adult survey, support from a counsellor was the most common type of formal emotional support received (22%); followed by support from a bereavement charity (20%); support from a GP/community health care professional (13%) and a hospital/hospice based healthcare professional (12%).

Two main providers of counselling were mentioned – charities, which provided counselling sessions, 24-hour helplines and online forums; and private counsellors, paid for by individuals. A smaller number of individuals had accessed a limited amount of free counselling through their employers or through the NHS. Peer support groups were also mentioned.

Many children and young people specifically referenced either a key individual or an organisation who helped them. The support they had accessed included 1:1 support, family sessions, and group support.

Counselling

Counselling was generally felt to be helpful for those who accessed it, and in some cases was described as a lifeline. Respondents spoke about the importance of being able to talk openly about their feelings and their new life, being listened to without judgement, and feeling “understood”. The value of speaking to somebody outside the family was also a strong theme in the evidence, particularly when they lacked a stable personal support network

“I had seen a few counsellors who wanted to analyse and “fix” and the person I now see is there to listen and guide which is more comfortable for me personally.” - Woman aged 18-30 whose husband/partner died of cancer (England)

“At the time I was receiving counselling it was good to talk to someone outside the family.” - Woman in her 70s whose husband died (cause of death not reported) (England)

“My counsellor really understood what I was going through” (young person aged 16-17)

Some organisations felt that continuity of emotional support from pre-bereavement to post-bereavement tended to work effectively when the person died in a hospice or other palliative care setting. Examples of best practice were given where hospices and other palliative care services had helped coordinate bereavement support offers and provided both practical and emotional support to people. However, some felt that even where hospices were involved, more could be done to start providing ongoing emotional support before the death.

Counselling was also felt to be helpful by providing tools and strategies to cope with everyday life and move forward.

“It helped me come up with a range of strategies to help me through everyday life” - Woman in her 40s whose husband and father-in-law died (England)

“It gave me the tools I needed to help myself and what to do in the future if I needed more help.” - Woman in her 40s whose grandmother died of a heart condition (England)

Young people similarly described the value of being supported to manage their thoughts and feelings, including being given practical strategies to remember the person who had died, for example memory boxes, books and toys. Some felt that counselling helped build their confidence – regular sessions and consistency in support were important in this regard.

“They always helped me no matter what they were doing” (young person aged 13-15)

Emotional support from peers

In addition to individual counselling, respondents described benefiting hugely from peer support groups, often organised by charities, which provided emotional support after a bereavement. The value of less formal mechanisms and activities which bring people together to provide peer/ social support was corroborated in the oral evidence. Witnesses described how it enabled people to connect with others with shared experiences, normalised grief, helped people talk through and make sense of experiences, and reduced loneliness and isolation.

There was a general reflection among organisations that the pandemic had led to innovation in the types of emotional support bereavement services offered, for example through expanded digital support. This was seen as a good development for accessibility for some groups, although not all are able to benefit (for example, the oldest old, who often experience digital exclusion).

“The impact of new technologies has been an important one for my service which was predominantly a face to face service prior to COVID-19. Having to adapt to online working has opened up the service. We adapted quickly, learning new skills in order to support our clients and we will be continuing to offer these choices in the future.” – organisational respondent

Those who attended online groups and forums overwhelmingly found their experience to be helpful and positive. Many felt these were particularly helpful where they were tailored to specific experiences of bereavement, such as those provided by WAY (Widowed and Young) - which provided individuals with the opportunity to talk about their experiences, but also feel less alone through hearing from those with similar experiences.

“Peer to peer support through a charity called Widowed and Young. Very powerful being surrounded by people in similar situations” - Woman in her 30s whose husband died in an accident (England)

“WAY widowed and young have been my lifeline for the last 3 years they should have more recognition for the contribution they do in helping those young and widowed.” Woman in her 30s whose husband died of complications of a pre-existing condition (England)

Children and young people that had accessed group emotional support similarly found it helpful to learn from others, and to feel part of a community:

“It also helped to hear about other people’s journeys” (young person 13-15)

“I liked [the service] with the other super siblings” (child aged 5-12)

Drop-in support

The oral evidence highlighted the benefits of other less formal types of emotional support for example drop-in Bereavement Help Points, which served mostly bereaved partners over 55. It was explained how the Help Points offer social support in a flexible and relaxed way and, in contrast to most services which are mainly used by women, these unusually attracted a 50/50 gender split.

“Men don’t like to talk about their grief. Men don’t engage in talking about their grief, and again, with that, I go back to our Bereavement Help Points. With a lot of them we have a 50/50 split of men and women. If you were going to ask me, “Why is that?” I honestly couldn’t tell you. We don’t advertise them particularly to men, they’re just advertised as Bereavement Help Points, and they’re open to everybody.” (Oral evidence)

Specialist support for children and young people

Parents also highlighted the value of services that coached them to have important conversations with their children; helping children to understand better what had happened; helping children to learn that it was ok to have fun even while grieving and tailoring support to their children’s needs.

“[The service] has helped with vocalising feelings and coping strategies aimed at her” age. (Parent of child aged 5 to 12)

Organisations described how this emotional support was a valuable form of early intervention, helping to avoid future suffering (including intergenerational trauma) and costs to families and society:

“For bereaved people who would benefit from bereavement support services but who don’t have access to this provision, grief can be particularly isolating, and they may go on to experience complicated grief as they struggle to cope with the emotional impact of bereavement. More formal input from statutory services, such as NHS mental health support may then be required which is a costly resource with significant waiting times for support in many areas of the UK. Funding to provide bereavement support as an essential, early intervention would prevent escalation of grief-related difficulties, the potential for long-term negative consequences from unsupported grief, and the need for specialist and costly support.” Oral evidence

Receiving support at the right time

Having access to the right emotional support at the right time was felt to be key, though what was considered the right time to receive support varied between individuals. Sometimes, the offer of emotional support was deemed too soon to be beneficial including during the immediate days to seven months following the death.

“First sessions (within 3 months) I didn’t really process or appreciate because I was so lost in my grief.” - Woman in her 50s whose brother and sister both died (England)

Needing time to process the death before commencing with counselling, being in too much shock, and not thinking clearly enough to have any benefits, were reasons given for feeling support was offered too soon. Some respondents also shared that they did not want to use the finite resource too soon

“Bereavement services remained unwilling to support me as had not been 6 months since my grandmother’s death” Woman aged 18-30 whose grandparent died of COVID-19 (England)

“I needed counselling immediately after the event and support afterwards” Man in his 40s whose wife died – cause not disclosed (Scotland)

Innovations during the pandemic

Services described how they had innovated during the pandemic, providing services by telephone and online.

These included:

- Online chat services
- Greater numbers of online/social media support groups
- Sending out packages of support, increased check ins by telephone.

The flexibility of online or virtual support had been positive for many services users e.g. reducing the logistical challenges of travelling to appointments, being able to email a query when it suited them, having access to practitioners by phone and having a responsive online presence. Many services highlighted that offering services in this way was a paradigm shift and has allowed services to be more creative in supporting children, young people and families, as well.

The oral evidence highlighted a number of further benefits of online/hybrid delivery. Respondents shared that online support can help fill a gap while people wait for face-to-face appointments and peer-support groups to start up again; podcasts, the online Good Grief Festival and apps (e.g. Grief Works) have helped people between their in-person appointments; online chat and groups reach new groups of people, potentially including younger people and can connect people with wider communities than local groups offer. Online options also afford greater control and flexibility meaning people can dip in and out as they like without feeling committed. The limitations of online delivery are discussed in the following section.

Organisations highlighted how they have been able to be responsive to families referred to the service and some have prioritised those assessed as vulnerable, offering outreach, engagement and support from referral onwards.

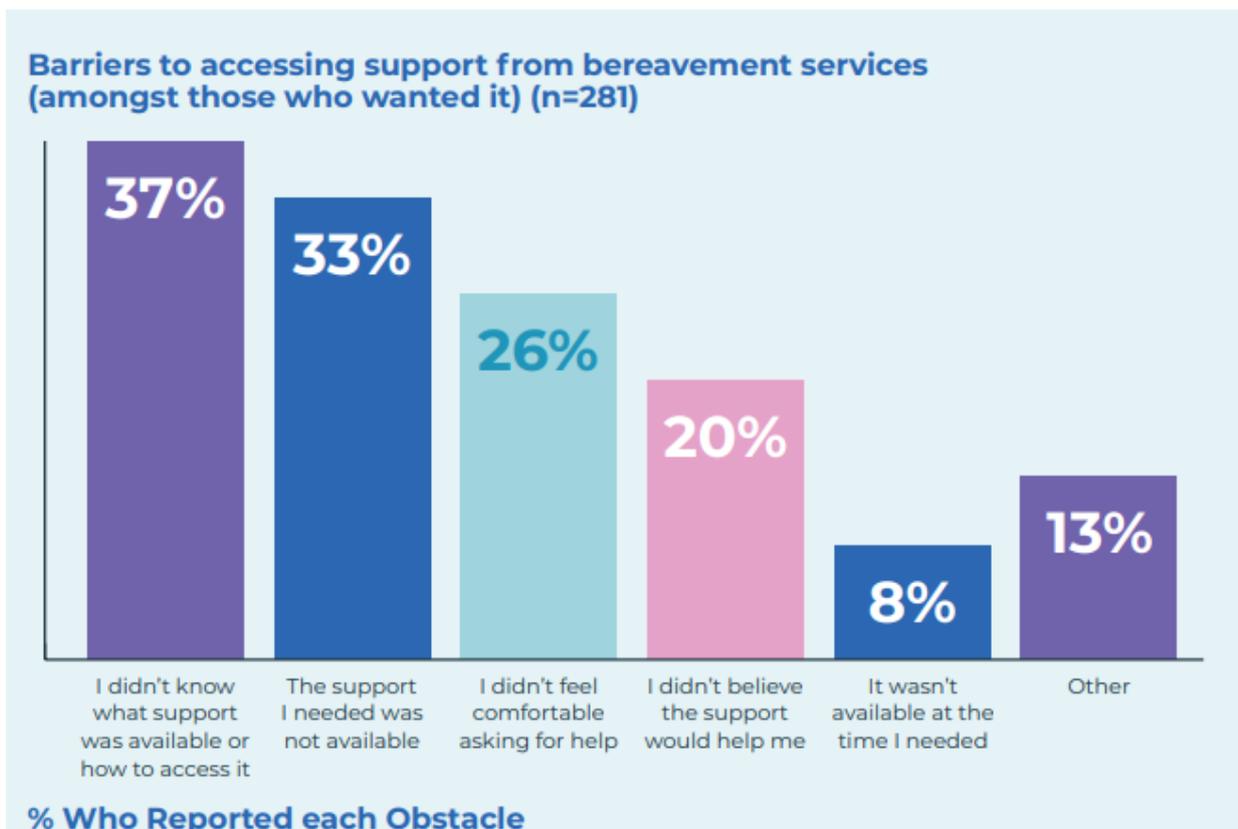
Additionally, this digital shift allowed services to communicate effectively with boards or other governance groups, allowing for agility in a changing external landscape. Services also appreciated working virtually with other external agencies, resulting in closer working relationships with key partners.

For all these reasons, many services are now tending to retain a 'blended approach' of online and face to face support.

Barriers to receiving emotional/psychological support from services

A wide range of barriers were identified in the evidence surrounding access to formal emotional support, both by those who had received it and those who had not.

For those who wanted to access some form of formal support, many (42%) did not receive it. Obstacles that prevented people from accessing support were reported by people who were certain they wanted professional support and by those who thought they might benefit but were uncertain. When presented with a list of common obstacles and asked to select all that applied to them, lack of knowledge of how to access support or what was available out top, followed by the support not being available and not feeling comfortable asking for support.

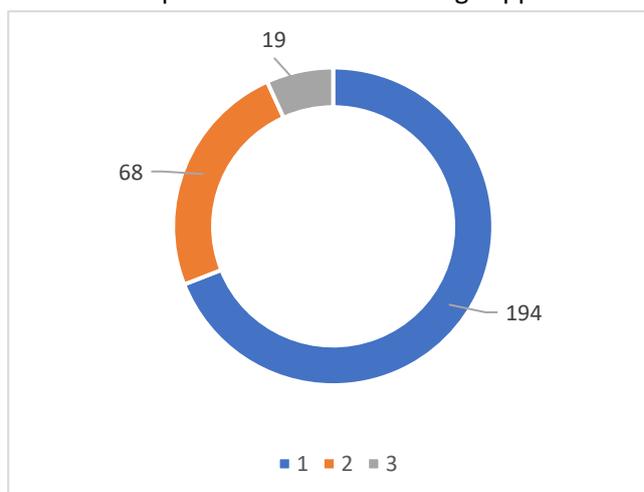


Total N = 281

As is clear from the data, a significant minority (31%) experienced multiple obstacles to accessing support. The full breakdown can be seen to the right (total N = 281).

Analysis was conducted to see if the demographic factors age, gender, LGBTQ+ identity, ethnicity, education level, sexual orientation, or nation of residence had an impact on how many obstacles someone faced. Most tests did not find a significant difference ($p > .05$). This does not mean that marginalized groups did not or do not face additional obstacles in accessing support, but rather that such additional obstacles may be highly variable to individual situations and hard to capture through broad questions. This is supported by qualitative evidence in which people from marginalized backgrounds shared difficulties they faced because of their identity.

One factor was flagged as significant: age¹².



¹² $\chi^2(8) = 27.17, p < .001, \phi_c = .18$

Those in the 31-40 age group received more informal support and those under 50 were more likely overall to access formal support services (see Appendix E for full details of all tests of group differences).

A number of barriers to accessing support were identified in the qualitative evidence. These broadly fell into five main themes; low awareness of support needs and reluctance to seek help; lack of awareness of available support; poor availability of support and lack of flexibility and choice of support; and pandemic-specific barriers.

2. Low awareness of support needs and reluctance to seek help

Lack of recognition of needs

Many organisations pointed out that younger children and young people are dependent on the adults in their life to access services on their behalf. Children and young people may not understand the voluntary or charity sector and may not necessarily have the skills or resources to search for emotional help themselves.

This requires adults (whether family, friends or school staff) to recognise the child's grief and their need for support. A lack of awareness of how children express their grief can lead to their needs being overlooked. Even if a parent or adult is aware of their child's needs, the child may not accept the support that is offered. Some young people did not feel that they needed help.

“Adults are ‘gatekeepers’ to their children; bereavement services only ever see those children where an adult in their life has recognised their needs; family ‘culture’ may mean that adults do not see the need for/value of bereavement support for a child/young person. Also, education establishments which are less bereavement-aware may result in a pupil/staff member not getting the support they need.” (Children’s bereavement support organisation)

“Grief can also be misunderstood and some children’s behaviours not identified as being grief-related.” (Children’s bereavement support organisation)

“There are a whole set of attitudes values around grief and bereavement that we have as a society and of course children are hugely impacted by those. So the position of the adult in the child’s life, a care giver a supportive professional, really, really critical but I think it’s really important for us to acknowledge that actually the type of support a child receives is very heavily weighted by the adults around them and that is critical”. (Children’s bereavement support organisation)

“My son had nothing. He refused help from Children and Adolescent Mental Health Services (CAHMS)”. (Parent of 5-12 year old)

“Didn’t want help” (13-15 year old)

Some respondents from the individual adult response survey also reported that they were not aware of their own needs. This seemed in particular to be where the death was perceived as traumatic or where a respondent had suffered multiple bereavements. Not knowing what could help made it difficult to accept offers of support.

“You don’t know what you need when hit by a death, or several in my case.” -Woman in 50s whose husband died of cancer

“I did not know I needed it but it was offered so I accepted the offer. I am so glad I did, it gave me a voice to talk about “my” grief and anything else I needed to “ - Woman in 60’s whose husband died of cancer

Stigma around seeking formal emotional support

An additional barrier to getting help was a sense of stigma around it. Several respondents described a perceived societal stigma around accessing formal emotional bereavement support, potentially viewing it as a sign of weakness, not wanting to “air dirty laundry in public”, or simply as not something that they felt they wanted to engage with. Respondents suggested this stigma was particularly acute amongst some groups. Children and young

people were also affected when there were differences of attitude about accessing bereavement support within the family.

Several respondents in the organisational evidence described the need for services that understand and respect the values and beliefs of different groups within our society.

“Have bereavement counselling that represents my values and beliefs as well as taking into account communication where English is not first language as can't really offer support via interpreter...Hospices hospitals etc not set up to offer bereavement support for people who are not white British and for those who don't speak English “I also think counselling has a bad press and is viewed by many as a sign of weakness. This needs to change.” - Woman in her 60s whose husband died of cancer (England)

“My husband is Black and there is a stigma around receiving support or speaking to someone about your grief. I begged him to see the GP or speak to employee assist but to this day he never has”- Woman in her 40s whose father in law died of cancer (England)

“Culturally, my parents generation don't “do” therapy” Woman in her 40s whose daughter died of sudden infant death syndrome (England)

“There is still under-representation among harder to reach groups. This could in some part be due to the cultural aspect where there may be stigma around help-seeking. This can be a vicious circle as it creates a barrier to showing how support is accessible to some groups, who may not want the fact they are receiving support to be in the public domain.” (Children's bereavement support organisation)

The individual respondents reported additional stigma when the death is not a family member, with perceptions of a lack of understanding from others.

“Understand that you can grieve just as much for a non family member, Woman in her 70's whose friend died of cancer” (England).

The oral evidence similarly highlighted that there can be stigma associated with grief and related help-seeking, in particular following suicide or abusive relationships. Stigmatised and disenfranchised grief can mean that people feel unable to grieve in the way that they want to and need additional support to be able to do so.

3. Knowledge and awareness of available support

Not knowing what support is available and how to access it

Both individual respondents to the Commission inquiry and organisations reported a lack of public awareness about what “bereavement services” were, how to access them, or what they could offer. There was a sense that unless they or a family member had previously been through a bereavement, they would have no idea what was available or how to access it. There was a lack of knowledge of the full range of options available, misunderstanding what formal emotional support would involve and a feeling that others' need for support may be greater.

“Define 'services from the bereavement sector'. I didn't know what help was available or how to access it, or what to expect. It was all complete new and frightening” -Woman in her 50s, whose husband died of cancer (England)

“

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

”

This was also the case for child bereavement services. Even when a parent or a young person recognised the need for support, finding it could be very difficult. Many young people and parents described the struggles they faced in understanding what was available, and some talked about how they had only found support by chance.

*“Our family did not get any signposts to any organisation.”
(Parent of 5-12 year old)*

“I went to the doctors when [my son] needed help and was just send a text of links to "support" there was no face to face information given or referred to anywhere.” (Parent of 5-12 year old)”

“I felt there were few options for me and I had no idea that there was any support routes for me out there. And the one I was made aware about there was no information on so I did not know the type of support it was going to be.” (Young person 16/17)

The pandemic disrupted usual referral routes: schools would often be a significant source of referrals to organised services but this slowed significantly while children were being schooled at home. People were less likely to access their GP during lockdown too.

Respondents also noted that the language that services use to describe the support they offer may not match the language that families use when searching for help.

*“Trying to get people to talk more openly about death by avoiding such euphemisms can serve as a barrier to people finding the support they need, as key words on web pages such as ‘death’ and ‘bereaved’ may not accord with the search terms people type (e.g. ‘I have lost my wife’).”
(Children’s bereavement support organisation).*

Not being offered support

Many respondents felt that the onus was on the individual to seek support, rather than services proactively reaching out to them to offer help. This was a source of disappointment for many respondents, particularly in reference to a lack of contact from GPs, or hospital teams that cared for the people they were close to before their death.

*“I never even had a phone call from my GP when my mother died, not even a letter, nothing from the hospital either other than the call that told me she had died... People should be given information on services and possibly given a number for a support or case worker to help them through this time should they need it.” - Woman in her 50s whose mother died of COVID-19
(Wales)*

In addition, the abrupt ending of support from services that supported the deceased person in life was another challenge which left people feeling unsupported. It was also explained how other close family members of the person who died may miss out on offers of support if the care provider is not made aware of them by the patient before they died.

“Hospice and district nurses were wonderful but suddenly gone when my wife died- understandable, but that left a big black hole.” - Man in his 60s whose wife died of cancer (England)

“Though our bereavement service is open to anyone connected to a patient, many still do not know this. We rely on patients sharing the contact information for those closest to them in order to communicate to them and offer our bereavement service. This information often doesn't reflect a patient's full support network and often many members of the family/friends are excluded.” – organisational respondent

Young people noted the practical and emotional burdens of seeking support, and some parents expressed disappointment around the failure of schools to proactively offer any support to their children through their bereavement.

Families struggling with the practical and emotional challenges of bereavement may not have the capacity to seek support proactively. This was worsened by the pandemic, with organisations describing how families were more reticent to seek support while they were also managing the challenges of home-schooling.

“I haven't explored it as much as my youngest's health has taken most of my energy.” (Parent of 5-12 year old)

“Delayed grief and delayed engagement with support services: whilst dealing with the challenges of the pandemic, many people ‘just ‘got on with it’ and only made contact if they were seriously struggling - now bereavement services are seeing increased demand from people experiencing ongoing mental health/wellbeing issues.” (Children's bereavement support organisation)

Organisations raised a concern that certain groups of people may be less likely to be signposted to support due to assumptions made about suitability, including people with learning disabilities. It was also felt that other groups may benefit from more proactive signposting due to attitudinal barriers to support seeking, such as older people.

“Other people may be put off seeking support because they feel others have a greater need, they are distrusting of services established by and for the majority population, or they do not believe that support will help them.” – organisational respondent

Many respondents also described how being unaware of how to access formal emotional support directly impacted on their mental health or experience of grief.

“Making it more accessible and easier to get. When you're grieving it can take all your strength to get up on a morning and brush your teeth”- Woman in her 50s whose husband died of COVID-19 (England)

“Services are not easily accessible, often GPs will just give out a leaflet and leave the onus on the person to self-refer which they may struggle to do when they are feeling anxious and depressed following a bereavement” - Woman in her 50s whose husband died of cancer (Wales)

In Harrop and Selman's national survey during the pandemic (n=711), just a third (34%) of respondents reported that a professional had provided information about bereavement support services either at the time of death or during follow up.¹³ Organisations also noted that information provision on available support was inconsistent and variable across care-settings, with much good practice in hospice and palliative care settings but generally not elsewhere.

¹³ Selman et al. 2022, Risk factors associated with poorer experiences of end-of-life care and challenges in early bereavement: Results of a national online survey of people bereaved during the COVID-19 pandemic. Palliative Medicine <https://journals.sagepub.com/doi/10.1177/02692163221074876?icid=int.sj-related-articles.citing-articles.1>

4. The availability of support

Not enough support available

A clear theme across the evidence was a perception that there was simply not enough emotional support to help people cope with a bereavement available. For some respondents, the impact of being faced with barriers when trying to access support meant that they stopped trying to access it and subsequently did not get the help that they needed.

“Please make counselling easier to access and embed it into standard bereavement care. I only attempted to access professional support once, via my employer, and was told nobody was available to help me so I never tried again. Reaching out during a deeply dark time was hard and difficult and to be turned away was even harder. Experiencing three deaths of family members in the space of less than 1 year, all during difficult circumstances, has left me with a huge amount of pain that I cannot overcome.” - Woman aged 18-30 whose grandparent died of cancer (Wales)

Contributing organisations echoed this concern, and highlighted the patchy provision of support.

“People have found it very hard to find/access bereavement support that is professional. In a recent discussion one person told me they had waited three months for an initial assessment for support and will need to wait another 2 months before she can start counselling.” – organisational respondent

“[Private] counselling is expensive and families can’t afford this for every family member.” – organisational respondent

Relatedly, organisations voiced concerns that not enough specialised emotional support is available – relaying fears that generalist support may not be appropriate for people who have been bereaved in particularly traumatic or complex situations, including during COVID-19. Some respondents felt that bereavement during COVID-19 was a unique experience unlike other forms of bereavement. As a result, there was a feeling that those who haven’t been bereaved during this period can’t understand the experience – and therefore that no one outside of this experience or lacking in specialist training could provide support. The oral evidence highlighted that grief counselling was typically not appropriate in the early stages of grief for people affected by a traumatic bereavement such as bereavement by suicide, as they required specialised support.

“I needed a much more trauma focused plan”- Woman in 40s whose mother died of COVID-19

The oral evidence highlighted the issue of inadequate bereavement support for child deaths, with one witness sharing:

*“We did a freedom of information survey of CCG’s. About the extent to which they were meeting the NICE guidelines on end of life for care for children. And standard five of that is all about bereavement support. And we were a bit shocked actually that only 40% had a service specification that met that standard. Which was we thought pretty awful. And I think only 37% had service spec around finding emotional and psychological support for families. And there’s a huge gap there. And we’ve noticed we’ve had Commissioners say to us there’s just no psychological support out there. I’m asking if you know if we can extend our helpline to do that.”
Organisational response*

Waiting lists and long delays

Even if people were able to identify sources of formal bereavement support, a number of obstacles remained. One of the most cited barriers across all forms of evidence, was the length of waiting lists for support.

“At the time there was nothing I was put on a waiting list for Cruse phone support. Hospital said they organise support groups but not running because of COVID-19. Not heard any more about support groups still not running” - Woman in her 60s whose husband died of COVID-19 (England)

“With long waiting lists for bereavement counselling, it's easy to just not bother trying to access it.” - Woman in her 50s whose mother died of dementia (England)

In addition to delaying access, organisations cautioned that long waiting lists can put people off seeking support altogether— and waiting lists were made longer by the pandemic. At the same time, NHS mental health services have become harder to access.

Lack of access to specialist mental health support for people with more complex needs was also identified as a challenge. Examples were given by organisational respondents of bereavement service clients with complex needs waiting 18 months for referrals to mental health services.

Ineligibility and regional disparities

The oral evidence highlighted disparity across the country. For example within hospice services there were differences in terms of whether or not local bereaved families can access their bereavement support services regardless of care setting or whether these were restricted to the families of hospice patients. Respondents also described a post-code lottery, whereby people living outside of catchment areas of locally commissioned services were unable to access support.

“We have hospices who say, “Well, if you’re under our care, no matter where you are, your family can access us, and where the other families, who instead, because they’ve died in hospital, were never referred to a hospice, sorry, you can’t come to us,”...People don’t know where to turn, there’s lots of red tape about who’s eligible” (Oral evidence)

The oral evidence also highlighted particular challenges associated with rurality noted in Wales and Scotland, with a particular lack of support services in North and West Wales and the relative isolation of communities living in the Scottish Isles also noted. It was seen as particularly important to capitalise on community infrastructure and local support networks to tackle these disparities.

Related to this, the evidence also identified the need to recognise the unique experiences of farming communities and high rates of suicide within these communities, which are particularly isolated and have limited capacity to support families after these deaths.

Having to seek private support

The delays, barriers and restrictions associated with accessing support through the NHS, charities or employee assistance programmes meant that some respondents sought, and paid for, private counselling for themselves or their children

“It only lasted for 8 sessions which was not enough, and then I was left to find my own private counsellor” A Woman in her 30s whose husband died of cancer (England)

“I’m fortunate that I can afford to continue counselling after the first free 6 weeks. However, 6 weeks was nowhere near enough, and I believe this would have stopped if I couldn’t afford it.” A Woman in her 30s whose daughter and grandparent died (England)

*“I ended up paying for a play therapist for my daughter out of my universal credit payments”
(parent of 5-12 year old)*

Both individuals and organisations highlighted that many people did not have this option, as they were unable to afford private counselling. The fact that free emotional support is not well funded increases inequities, worsening access for those on low income or in financial hardship.

“Because I can afford to pay for counselling that has really helped. Others are not so lucky” A Woman in her 30s whose husband died of a life limiting condition (England)

“I do think I would benefit from some type of trauma counselling (EMI) or similar, as I still appear to get PTSD symptoms around his anniversary. However, this is massively expensive and I cannot afford it.” A Woman in her 40s whose son and grandparent died (England)

This reliance on privately funded support, combined with regional disparities in the availability of free services, may therefore explain research findings shared in the oral evidence, that a fifth of people on lowest incomes felt unsupported after bereavement compared to 10 per cent of those who were in the highest income groups.

“And we identified that as people have talked already about inequalities and diversity and also I'd just like to introduce low-income into that picture as well because we certainly found in our survey that there are a fifth of people on the lowest incomes felt unsupported after bereavement compared to 10 per cent of those who were in higher, highest income groups” Oral evidence

These findings may also reflect the financial challenges many people faced following a bereavement – as discussed in detail in chapter seven.

5. Lack of flexibility, choice or support suited to individual needs

Accessing support too early or too late

For both adults and children, the **timing** of emotional support was a problem, with three different perspectives expressed:

- Support offered too early
- Support offered too late
- Support offered only for a set period which didn't fit the non-linear journey of their grief

For those who thought they had not received emotional support soon enough, timelines were generally within 6 months but ranged up to 12 months. Some people were told they had to 'move on' from the death before receiving support and could not access it while in early stages of grief. This led to feelings of being let down and isolated.

Adults, children and young people talked about how their grief was not linear and changed over time, which could mean that services were needed later, whereas for others, waiting for support had been problematic. Some also commented that the duration of support was too short (e.g. 6 weeks) and they would have valued ongoing help.

Organisational participants in the oral evidence session suggested that an offer of emotional support to cope with a bereavement which was too early may be off-putting, with people lacking the capacity to engage so soon after a death. They highlighted the need to ensure that people know services will be there throughout the entirety of their bereavement journey.

“Took too long so when I received it I didn't need it” (16/17 year old)

“I didn't want to talk about it for a long time afterward so it's important to remember that they need time to process it and they can process it on their own but still help them process it together” (13-15 year old)

“For me needing support a lot later down the line as it’s been 2 years now & I have found the grief has gotten worse with the missing sadly. Trying to rebuild one’s life again is so hard.” A Woman in her 50s whose husband died of cancer (England)

“Any help from NHS was only offered 7 months following mums death and this was as part of complaint made to the NHS Trust.” A Woman in her 50s whose mother died of septic shock (England)

In the oral evidence it was also explained how funding constraints and limited availability of services compromise the timeliness and potential for person-centred support.

Limited number of sessions available

For those who were able to access formal emotional bereavement support, disappointment was expressed regarding the limited number of sessions that were available to them. Many respondents described wishing that the sessions could have been extended.

“The sessions I had helped somewhat but after 6 sessions I was told I was fine and didn’t need it. Which wasn’t true but I now feel like I shouldn’t be wasting anyone’s time because of this.” (16-17 year old)

“I am heartbroken children are heartbroken. 1 hour of counselling once a week for 10 weeks is not enough. Its doing more harm than good. I am left emotionally drained and somewhat worse than before I started the counselling as it is a form of abandonment when the call ends its rushed and to much of a time restricted affair. We need a place where we can relax and not feel like a race is about to end” A person in their 50s whose mother and father died (England)

“Organisations like Cruse and the Hospice bereavement services do a wonderful job but their support is limited, there seems to be a lack (or maybe a perceived lack) of ongoing support. Bereavement is not over and done with after your allotted sessions.” A Woman in her 60s whose husband died of cancer (England)

Limited times available for support sessions

Another barrier affecting access to support was not being available at the time the sessions were offered due to work or caring responsibilities.

“I couldn't attend sessions when I returned to work as they were either during my working hours or at my children's bedtime when they needed me the most. There was very little on offer local to me and I couldn't find any sessions that my children could attend with me” - Woman in 40s whose husband died of heart disease

“There are a lot of hoops to jump through, not enough support at difficult times such as evenings and weekends and I could not find support specific to me”- Woman in her 40s whose mother died of an untreated infection

Those with full-time caring responsibilities had more long-term time difficulties, due to the 24/7 nature of their commitments.

“I was offered support from the Hospice as my husband died six months after my daughter and I had been unable to access help earlier as I was caring for my husband.”- Woman in her 60s whose daughter died of cancer

Those struggling with times also struggled with location and reported that they would have been able to receive support at home.

“My mother’s GP asked if I wanted bereavement counselling, but I had my Mum’s dog and my own dog to look after Home visits would have helped, but when I asked for help in the past, I never got any.” - Woman in 60s whose mother died of cancer

Inaccessibility of online/telephone support

Choices regarding the type of support offered changed during the pandemic. COVID-19 restrictions forced a shift to online support rather than face to face. Though some welcomed this change and it opened up new possibilities, it was not accessible to everyone.

“I needed human contact but was abandoned. Helplines are not helpful especially when you have to spend a prolonged period on hold.” - Woman in her 60s whose husband died of cancer (England)

Many respondents found engaging with online or telephone support difficult; reasons included lack of privacy if making the call from home, not being able to establish rapport with the counsellor, or disabilities such as hearing impairment, which make accessing online or telephone support difficult.

“I had to have the support over zoom which was extremely difficult as had to find somewhere to go that was private.” -Woman in her 50s whose husband died of cancer (England)

“It was good to speak to someone, but I felt it was a barrier via telephone and couldn’t ever fully express myself. Plus, only allowed a short number of sessions. So, feel like there is more to deal with.” - Woman in her 40s whose grandparents, sister-in-law and daughter died (Wales)

“Due to her hearing problems, she needs face to face support” - Woman in her 60s whose cousin died of cancer (England)

Organisations in the oral evidence warned against support being available online only – as this is not suitable for everyone, including many older people and people with learning disabilities. Some respondents suggested that virtual settings can potentially conceal a person’s feelings and reactions to the therapist or counsellor, by clouding body language and facial expressions. There is a need for more research to understand more about how effective online bereavement support is.

Support not meeting individual needs

Even when people had accessed the services available, these did not always meet their needs or expectations. Respondents found some individual grief counsellors unhelpful for a wide range of reasons, but there was a consistent perception that emotional support on offer wasn’t always sufficiently tailored to children’s ages or experiences.

“Our practitioners tell us that in many cases, children and young people are only able to access general bereavement services that don’t always meet their needs” (Specialist Children’s bereavement support organisation)

“Hold individual sessions as I have not been able to let everything out as my family is in the room” (13-15 year old)

“I went to counselling but it was so boring” (5-12 year old)

“She didn’t find talking therapies very helpful. She needed distraction and bringing up memories in a gentle way.” (Parent of 5-12 year old)

“Too often services feel inaccessible to them because they are built around an adult lens of what adults think children’s issues are” (Children’s bereavement support organisation)

“My youngest attended 1 group session at 8 years old, every child there was 5 or under, total waste of time for him. Support groups for different interests. He doesn’t want to sit & colour in pictures, he wants to be outside playing sports in all weathers” (Parent of 5-12 year old)

*“Not much [support available] as the services local to us now start at 11 and not younger.”
(Parent of 5-12 year old)*

*“All of the free support is either full or more aimed at older people or young children there isn’t a really space where young adults are welcomed to meet with others going through the same.”
(16/17 year old)*

6. Additional pandemic-specific barriers

The oral evidence highlighted Harrop and Selman’s research into pandemic bereavement experiences, which identified high levels of unmet need for support amongst vulnerable research participants (those whose circumstances may increase their risk of more complex grief), but also found that around half of these vulnerable participants hadn’t tried to access services.¹⁴ The Adult Attitude to Grief scale (AAG) was used to define vulnerability in grief.¹⁵

This study also found that the pandemic continued and likely exacerbated many of the known barriers to accessing formal emotional support services, such as those described above, including unavailability, lack of knowledge or understanding of support, feeling uncomfortable seeking help or unentitled to support at a time of crisis. Only a third of the bereaved research participants had been given information about bereavement services following the death. The study identified similar unmet needs and barriers to support-use in children and young people, as reported by parental participants in the study.¹⁶

“Around a quarter of parents described needing additional support from bereavement or mental health services for their children and in just over a third of cases they weren’t receiving this support. Reasons why children weren’t getting the support they needed included lack of availability or delayed referrals to mental health services due to the pandemic, long waiting times for bereavement services support, not knowing how to get support, preferences for face to face support and also some resistance from their children to receiving external support, so some similarities to some of the adult practice as well.” organisational response

¹⁴ Harrop, E., Goss, S., Farnell, D., Longo, M., Byrne, A., Barawi, K., Torrens-Burton, A., Nelson, A., Seddon, K., Machin, L. and Sutton, E., 2021. Support needs and barriers to accessing support: Baseline results of a mixed-methods national survey of people bereaved during the COVID-19 pandemic. *Palliative medicine*, 35(10), pp.1985-1997; Selman et al. 2022, **Risk factors associated with poorer experiences of end-of-life care and challenges in early bereavement: Results of a national online survey of people bereaved during the COVID-19 pandemic.** Palliative Medicine

<https://journals.sagepub.com/doi/10.1177/02692163221074876?icid=int.sj-related-articles.citing-articles.1>

¹⁵ <https://mapping-grief.care/guidance-for-practitioners/the-adult-attitude-to-grief-scale-aag/>

¹⁶ Harrop et al. Parental perspectives on the grief and support needs of children and young people bereaved during the COVID-19 pandemic: Qualitative findings from a national survey [preprint] 2021. <https://www.medrxiv.org/content/10.1101/2021.12.06.21267238v1>

Quantitative Insight

A correlation was conducted to test if disruptions faced during Covid-19 were related to the types of support which reached individuals. The correlation was significant¹ and showed that the fewer avenues of support that reached individuals, the more disruptions they faced. It seems likely that this was because circumstances such as lockdowns both decreased support access while increasing difficulties in a “typical” death and bereavement and serves as a reminder of the heightened level of distress and isolation bereaved individuals have experienced in recent times.

¹ $r(758) = -.11, p = .002$

Organisations responding to the Commission similarly described how people bereaved due to other illness/causes during the pandemic felt less justified in their grief and less entitled to support than people bereaved by COVID-19. Some people bereaved by other causes felt forgotten about and overlooked in their grief, perceiving that attention and support overwhelmingly focused on COVID-19 deaths.

“There has been a lot of focus on COVID-19 bereavement. A lot of support groups are focused on this. As a person who was bereaved during COVID-19 but not by COVID-19, it does feel like we don’t have the same support or sympathy”. – Woman in her 30s whose sister died of a brain aneurism, (Northern Ireland)

Organisations also highlighted the impact of delayed grief and delayed engagement with support services: while dealing with the challenges of the pandemic, many people ‘just got on with it’ and only made contact if they were seriously struggling - now bereavement services are seeing increased demand from people experiencing ongoing mental health/wellbeing issues.

Additionally, some respondents commented on how it was harder to end formal support, with some who have had sustained support through the pandemic finding it harder to let go of the support.

“In terms of deaths related to COVID-19, there can be a lack of understanding of the specific and painful circumstances in which a loved one has passed away. The scenario of this coronavirus pandemic has created situations which are unique, with issues such as a lack of physical contact and being in the room in a person's final moments particular issues.” – organisational respondent

“The level of emotional distress at not being able to be with a loved one at the end of life has also impacted many people’s acceptance and experience of bereavement.” – organisational respondent

Organisations described how some young people had taken on additional responsibilities in the family while there was limited practical support available, and that this might have further inhibited them from voicing or prioritising their own emotional support needs.

The pandemic restrictions also put additional pressures on service delivery. There were practical challenges shifting to remote provision including setting up IT systems and training staff and volunteers too. However, there were also challenges returning to face-to-face support after the pandemic including logistical challenges around coordinating lateral flows and risk-assessments for returning to face-to-face work and finding rooms with sufficient space for social distancing; as well as a nervousness and hesitancy amongst volunteers about going back.

Change needed to improve formal emotional/psychological support

Despite the challenges people faced, respondents highlighted a number of changes which could make it easier to find and access suitable bereavement support services.

Improving recognition of needs and attitudes to seeking help

Recognising that there is often stigma attached to seeking support from bereavement services, organisations highlighted the importance of influencing public attitudes to help families and professionals understand grief and support needs, and to increase the acceptability of help-seeking.

*“In order to improve access to services we need to improve the conversation around death, if people believe it is “ok” to feel a certain way and it is “good” to look for support they will find it.”
(Children’s bereavement support organisation)*

“Acceptance that sometimes support outside a community would be helpful, that it is not a weakness or something that should always be dealt with, within a community.” (Children’s bereavement support organisation)

*“An understanding that withdrawing and anger might both be signs of someone not coping with their loss as a young person. Anger gets attention (in the wrong way) and those who withdraw often are not offered support in school as they are not causing a problem with their behaviour.”
(Children’s bereavement support organisation).*

Increasing awareness about what is available

Recognising that many people were unaware of bereavement support available, respondents to both the individual and organisational surveys emphasised the need to ensure that up-to-date information about bereavement support services and how to access them is widely and consistently available.

*“Make it more widely advertised. I don’t know what support is available or where to find it”-
Woman in her 30s whose husband died of organ failure (England)*

Across all the evidence there was a call for better mechanisms for signposting and referring to support. These broadly related to publicity, synthesis of support sources, and proactive outreach.

Publicity

Many individual and organisational respondents highlighted the need to increase the availability of information in places where people already spend time, presented in different languages and accessible formats, and to include information about eligibility requirements for each service. They suggested information should be available online (e.g. council or NHS sites) and in physical community settings such as GPs practices, pharmacies, libraries.

Signposting

Signposting was a dominant theme in the individual evidence, and participating organisations acknowledged that the need for improved information and signposting is an ongoing challenge for the sector.

“People want face to face support groups and one to one counselling. Trawling through the internet to find these is very hard when grieving. Local help needs to be better signposted and specific details of who they will help and where you have to live and the circumstances of death - so you are not phoning up endless organisations to be told you are not eligible.” – organisational respondent

With more proactive information-giving and signposting, better information publicly available, and better access to less formal sources of community support, such as peer support groups and Bereavement Help Points, there should be less need for people to visit their GP requiring mental health support.

A number of suggestions were identified for roles or organisations that could signpost to services, these included: funeral directors, undertakers, GPs, hospital teams, registrars, and the coroner’s office. Such interventions could include;

- Providing information about formal bereavement support along with the death certificate.
- Early signposting to specific support e.g. support/ advocacy for going through the coronial process
- Using Tell Us Once as a gateway to information about support available – could send a follow up reminder 3 or 6 months down the line

Some organisations suggested that it would be helpful to develop a set of standards for signposting to ensure that everybody gets the information that they need at the point of bereavement. This should include practical information as well as information on what bereavement support is available and the different types of support that are available, recognising that people have different preferences and needs and supporting individualised care. The Scottish example of practical information leaflet ‘What to do after a death’ was mentioned as being helpful but not widely distributed. Organisational respondents suggested that health boards and those working in healthcare settings need to understand and be aware of what services and support offers are available in each area. Good Grief Trust and At a Loss here as they both offer searchable directories of bereavement support in specific areas and by bereavement type the evidence implied these were not widely known about.

“Would be good to have one directory of services available as although we have information on services these do change over time.” – organisational respondent

Many respondents felt that the timing of communication also needed to improve – in particular current practices of providing a leaflet containing information services close to the time of death were not especially helpful without later follow up. There were suggestions for health-visitor type approach where families proactively linked into a support system following the death, that can be called upon if and when needed.

“Advertise the service.. giving a leaflet when your loved one passes is not the right time. Most people throw it away or lose it.” - Woman in her 40s whose mother and father died (England)

Respondents to the commission inquiry also highlighted the need for better communication about bereavement support services to children and young people, including through schools and other community settings, and online:

“Helplines should be advertised more so others are aware of different kinds of support which is available for young people.” (16/17 year old)

*“Improve tagging in search engines including using the language people use when searching”
(Children’s bereavement support organisation)*

“There needs to be better signposting to service provision – in addition to online sources (e.g. Child Bereavement UK and Childhood Bereavement Network directories, AtaLoss.org etc.) information and signposting should be available in all public-facing organisations such as schools, GP surgeries and other community spaces.” (Children’s bereavement support organisation)

“I like the concept of the At A Loss website; I do think that there is more that could be done to promote this and increase awareness as its an excellent resource. Make more people aware of it and ensure that it is the go to place.” (Children’s bereavement support organisation)

Organisations also cautioned that universal services like helplines need to be equipped to support those presenting with complex needs, including mental health needs. Therefore, there is a need for staff in these services need to be confident in supporting these people and to know which specialist services to refer them onto.

Proactive referrals and continuous sign-posting

It was suggested that access to formal emotional bereavement support could be improved by taking a more “proactive” approach to communication.

“I doubt it is possible but a proactive approach from grief/bereavement services for those that are too proud/scared/in denial to search for support” - Woman in her 50s whose mother died of COVID-19 (England)

Organisations suggested that GPs might provide information about how to access support initially, and that information should be given at multiple points, early on and later. It was suggested that funeral directors,

communities, medical examiners, council workers (when registering a death), libraries, financial services staff could all signpost to emotional support – so that there are multiple opportunities for people to take up the offer. There was discussion of the role that different health care teams and GPs could have in referring for support.

“GPs could refer people for counselling services. I know not everyone visits the doctors if they have been bereaved, however if they do, could GPs put in a referral to a relevant charity service and ask the service to call the bereaved person? Being sent away from the doctors with a leaflet for bereavement counselling is somewhat unhelpful, getting the courage up to ring and explain what's happened can be so painful. If someone who's calling already knows a little bit about what's happened and calls the bereaved person it takes away some of the anguish and the onus isn't all on the bereaved person who is already completely overwhelmed.” - Woman in her 40s whose husband died by suicide (England)

Some young people and services also emphasised the importance of proactive approaches:

“Hospital/hospice should offer support for families, should make it the norm and then people could opt out of it” (13-15 year old)

“GPs are the main people are the people who know what is going on with families. It would be good if support was stemmed from them to inform individuals and families of support available to them following a death.” (Children’s bereavement support organisation)

“Notification via schools and first responders” (Children’s bereavement support organisation)

Improvements around timing

The importance of the timing of emotional support for both children and adults who have been bereaved was clear from the evidence collected.

Grief is not a linear process and people require different types of support at different times. Our evidence suggests that it may be better to view support needs as a constellation of needs and of help (formal and informal) rather than a singular occasion. Rather than providing a one-time offer of support, people may benefit from repeated opportunities to access and re-access support when needed (including if help is initially turned down). This may be particularly true around anniversaries or milestones such as the anniversary of a death.

Times when people felt they needed help the most also varied, ranging from pre-bereavement to two years post-bereavement. However, the need was often felt at specific time-points such as following the funeral. Informational support early on, signposting access to more formal emotional support, and offers of earlier support for people experiencing trauma is crucial.

“I was referred by GP for support when my husband was diagnosed as terminal, but I was told I wasn't depressed enough! I then felt like I did a lot of my initial grieving whilst my husband was alive but without anyone to talk to about it... I felt totally lost for the first month after he died as everyone said it's too early for counselling” - Woman in her 40s whose husband died of cancer (England)

Organisations in the oral evidence similarly advocated the importance of choice over when to access emotional support, including the opportunity to take up support after initially turning it down and being able to continue with the support after the prescribed endpoint if individuals felt that it will be beneficial. If people are having to wait for structured emotional support, it is important to provide a prompt initial response, and to continue to engage with them while they are waiting.

“Often people just don't know what's available for them at whatever point they happen to be in. So whilst it's always incredibly difficult to find that right way of providing that availability of support, it feels to me that there is an opportunity to knit all of that support that is available together” Oral evidence

Increasing the amount and type of support available

Organisations advocated for greater capacity to offer support to more people and for a longer time, arguing that rationing of support to a given number of sessions can be limiting. It was also suggested that support offered should be more holistic and diverse, including both practical and emotional support, and choice on the mode of delivery (face to face or remote). Peer group support and one to one counselling should also be offered, noting that resourcing support groups for those with similar experiences of bereavement was important.

Many children, young people, parents and organisations wanted support to be available to all children and young people who needed it.

“Each area should have dedicated child bereavement specialists who could support / counsel if needed” (Parent of 5-12 year old)

“Give them somebody to give them emotional support” (13-15 year old)

“Having a local community bereavement service open to everyone could help with this” (16/17 year old)

“There is no support for children who have no link to a hospital or hospice. My husband died in a road collision and there is no free therapy anywhere for my children. All children should have access to free therapy when they lose a parent.” (Parent of 5-12 year old)

“Counselling should be offered as standard. It is very difficult for the surviving partner to be searching for support for their children” (Parent of 5-12 year old)

“Increase in support options/services available locally and nationwide – ensuring every bereaved individual has access to at least one service from statutory/3rd sector organisations” (Children’s bereavement support organisation)

This required sustained funding - with some respondents highlighting that investing in bereavement services would save costs elsewhere:

“More funding for services like [name of service] as they help a lot and the support is great but with more funding they could help more young people in a similar situation” (13-15 year old)

“There simply has to be more financial support - particularly for the smaller local charities who are swamped with requests for help that they cannot meet the demand” (Parent of 5-12 year old)

“Funding to provide bereavement support as an essential, early intervention would prevent escalation of grief-related difficulties, the potential for long-term negative consequences from unsupported grief, and the need for specialist and costly support.” (Children’s bereavement support organisation)

“Funding for bereavement can be seen as an investment in peoples wellbeing and can also be looked at in terms of opportunity cost, that is to say by spending X on Bereavement we will see a reduction in costs in other areas.” (Children’s bereavement support organisation)

Need to improve suitability of services for children and young people

There is a need to make services more appealing to children by involving them in co-design. Inclusion of lived experience is key to ensuring that these offers reflect what is needed, particularly from those who are currently underserved by the sector.

“So we need to make sure what we are doing, absolutely everything, is more and more accessible from the imagery, to the language used to the ability to refer all these things need to be more adapted to children and young people (Children’s bereavement support organisation)”

“Putting people with experience in the driving seat of what you want services to do, they will tell you what it needs to do and then it can’t be wrong because it is based out of lived experience. We waste too much time on things not set up to work because we are not meaningfully making sure lived experience is heard” (Children’s bereavement support organisation)

“Actually if you sit and ask children and young people what they need they will tell you straight away, they are literally the best people to ask. We need to design something because they know how they want it done and that’s what we’ve been doing with our project” (Children’s bereavement support organisation)

“To improve access to certain groups, we need to work with them directly to ask what they want to be provided.” (Children’s bereavement support organisation)

Respondents felt that it was important to offer a choice of support to children and young people, including different activities and different modes of delivery, as well as age specific services. Children and young people responding to the commission spoke of wanting fun things to do, opportunities to do the things they had enjoyed doing with the person who died, and to spend time with others going through similar experiences.

“A more accessible or wide range of support, as I felt there were few options for me” (16/17 year old)

“It is paramount to remember that bereavement is specific to the individual and so any service needs to be flexible and broad.” (Children’s bereavement support organisation)

“Different mediums of talking therapy. Speaking vocally + face to face was almost impossible for me, but if I could text someone that would have been an easier way of communicating.” (13-15 year old)

“Some families are still keen to have face to face support and this should always be a possibility for those who seek it. How bereavement support is delivered should be a matter of individual choice.” (Children’s bereavement support organisation)

“I also do not drive so more local based help would make all the difference to my children. They do not want to use Zoom calls etc and they need local activities to help them connect to others going through similar experiences.” (Parent of 5-12 year old)

Respondents described a further need to provide specialist support for children when the death of a birth parent precipitates a move into kinship, foster or residential care, or adoption, and for those whose birth parent dies while they are in care. The need for appropriate support for those bereaved traumatically (including unaccompanied asylum seeking and refugee children and those bereaved by domestic homicide) was also emphasised.

Loss specific support

There was a call throughout the evidence for more loss-specific support, especially for those who had experienced more traumatic bereavements, and evidence was shared of existing and emerging examples of practice in this.

i. Pregnancy loss and child deaths

A specialist national bereavement care pathway for those who experience pregnancy loss or the death of a baby up to one year old is being rolled out in England and Scotland.¹⁷

The pathway aims to provide two elements of bereavement support: firstly, appropriate care and support in hospital, as usually – but not always - these deaths occur within settings or under midwife care. Secondly, the pathway aims to support and educate primary care and other community support, as there is currently a lack of community-based support after the family leaves the hospital setting.

“There’s something called the National Bereavement Care Pathway. And that’s being rolled out in England at the moment and introduced in Scotland. Which is about care. It’s got five different pathways for different types of pregnancy loss and baby deaths from miscarriage. The very early stages right up to death in infants up to one year old. And then the hospitals where that exists it really has improved care but then you find once you leave hospital the support in the community just isn’t there. I think there’s a really big role for skilling up GP’s in this area as well. We know that one of our pilots for the National Bereavement Care Pathway did some really good work. Working with a network of local GPs, it made a big difference. So it’s also about kind of supporting. One it’s more specialist but two it’s supporting the wider sector to be able to understand about different kinds of loss and support people. And also have places for them to be referred onto because that’s a bit of a gap at the moment.” Oral evidence

i. Suicide

Individuals and organisations recognised the need for specific support and trauma therapy available to all people bereaved by suicide.

“I think that anyone bereaved by suicide should get 1:1 support from a specialist therapist. It’s such a specific loss that you need that support.” - Woman in her 30s whose father died by suicide (England)

The oral evidence highlighted the importance of accommodating non-linear pathways as people have different support needs at different times and may come in and out of a support service.

“People will, may come to support and to different kinds of support at different times in their journey, and it may be that as anniversaries come round, people want to access support and need to be able to, I suppose, to come in and out of a supportive service, that it’s not a ‘you’ve had your support and it’s time to kind of move on’.” (Oral evidence)

ii. COVID-19 deaths

In addition, many respondents called for access to specialist counselling for those that had been bereaved as a result of COVID-19 due to the unusual aspects of their loss (eg not being able to say goodbye, limited visiting, impact on funerals).

“I think the COVID-19 bereaved are a very special group. I think there should be targeted support for us. Ideas to fill that gap of longing, regret and desperation.” -Woman in her 50s whose mother died of COVID-19 (England)

“I was sent information about Cruse and the Samaritans. And that’s it. I am a trained Cruse counsellor and a trained listening Samaritan and I am very experienced in working with bereaved people, I know without a shadow of doubt that well-meaning volunteers, however thoroughly trained, are not equipped to deal with the trauma and complexity of the grief caused by the death of a life partner to COVID-19.” -Woman in her 50s whose husband died of COVID-19 (England)

Meeting the needs of underserved groups

The above section has described the more universal challenges experienced by bereaved people accessing the emotional and psychological support that they may need from services, as well as some of the steps that could be taken to address these. However, the evidence also highlighted the more specific needs and difficulties experienced by particular populations who we know to be currently 'under-served' by bereavement services, and to have particular unmet needs for formal support.

The challenges and barriers to support experienced by underserved groups

Lack of culturally appropriate support and support tailored to underserved groups

Both the individual and organisational evidence highlighted that some groups and communities faced particular barriers to accessing bereavement services.¹⁸ A general lack of support for particular social groups or bereavement situations was emphasised in the organisational evidence including older people, ethnic minorities, people who are socio-economically disadvantaged, bereaved parents, those in need of longer-term intensive support, and LGBTQ+ individuals. This section is focused on the experiences and needs of racially minoritized communities, people with learning disabilities, LGBTQ+ people, people who are in prison and people who are homeless.

“These services are still predominantly staffed - esp. at executive level - by white people who cannot relate to our lived experience of living in a country that is so hostile to our skin colour and/or faith. They simply lack the knowledge and expertise to offer constructive support.

Other options include using the primary/native language of a community, esp. for older generation, and funding local grassroots movements to provide this support.” – Woman in her 30s whose mother died of a blood disorder (England)

“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” - Woman in her 30s whose father died of COVID-19 (England)

The experiences and needs of Black, Asian and ethnic minority communities

Respondents highlighted that minoritised racial and religious groups are less likely to access formal support. Respondents believed that in many instances this was due to lack of appropriate support being made available.

“A recent mapping of ethnic minority mental health services in the UK found that ethnic minority groups were less likely to use mainstream bereavement support services. Access issues and a lack of cultural sensitivity in the way services were designed so they did not meet the needs of specific communities were cited as barriers.” – organisational respondent

Mainstream support is not often culturally aware or faith sensitive. Eurocentric practices were seen to be the norm by survey respondents who reported that mainstream services which have a secular emphasis can feel exclusionary. At the interfaith roundtable held by the commissioners, witnesses highlighted how there are few organisations that provide faith-specific emotional bereavement support and a lack of bereavement support organisations in the community that are tailored to different religious backgrounds.

This lack of access is concerning, especially as the pandemic has particularly affected people from Black, Asian and ethnic minority communities. This heightened impact is not only seen in the disproportionately higher numbers of

¹⁸ L. E. Selman, E. Sutton, R. Medeiros Mirra, T. Stone, E. Gilbert, Y. Roulston, K. Murray, M. Longo, K. Seddon, A. Penny, C.R. Mayland, D. Wakefield, A. Byrne, E. Harrop 2022. “Sadly I think we are sort of still quite white, middle-class really” – Inequities in access to bereavement support: Findings from a mixed methods study. Palliative Medicine (in press).

deaths and bereavements¹⁹, but also the consequences of the restrictions with regards to people being unable to travel overseas to visit dying relatives or attend funerals, to fulfil wishes relating to repatriation of bodies or have family members from abroad visiting the UK for funerals, in addition to the earlier described disruption to mourning rituals. This has added to the emotional burden on people from these communities, preventing them from being able to grieve in the way that they would like and expect.

“There's not many bereavement support organisations out there in the Muslim community who provide faith specific Muslim bereavement support. I think it's growing but it's not there it's very, very sparse in some areas of the country and if everyone who wanted Muslim bereavement support from the Muslim community wanted it, you would find 95% will not be able to find someone, in my opinion. So I think that that needs to be looked at.” Oral evidence

Language barriers are another problem, with most services only being offered in English.

“My mother has not accessed counselling. She found talking about her issues was more triggering. There was a language barrier as English as a second language but did not always feel comfortable talking via a translator” – Woman in her 30s whose sister died of COVID-19 (England)

One respondent reflected that some bereaved people from minority communities would prefer to receive support from someone outside of their immediate community for confidentiality reasons. Gypsy and Traveller communities living on sites find it difficult to get enough privacy to access remote counselling support. Waiting lists and delayed access to support is a particular problem for Gypsy/Traveller communities living a nomadic life, as they may have moved on by the time it becomes available

The experiences and needs of people experiencing homelessness

The oral evidence revealed that homeless people commonly experience bereavement (in particular sudden, unexpected deaths), intersected with other trauma and health problems, making it especially hard for them to cope. They also commonly experience difficult relationships with biological families meaning that they may not learn of close relatives dying for months or years after the death and their support networks are also limited as many of their friends and family may also struggle with trauma or substance misuse.

Lack of access to technology, and perceived insignificance of their relationship status, means that homeless people often don't receive satisfactory information about people who are dying or died. They are often not invited, or unable to attend, funerals and memorial services which compounds their grief, feelings of shame and excludes them from normal grieving process.

Respondents also spoke of a dehumanising tendency amongst some non-specialist services – with a perception of homeless people as being resilient or having experienced so much trauma that a bereavement is less significant

People with learning disabilities' experiences and needs

Respondents highlighted specific challenges facing people with learning disabilities, including that they are not always told that friends or relatives have died, or may not be allowed to attend their funerals. It was suggested that there was a common misperception that they won't understand and therefore won't grieve and don't need to talk about their bereavement or be supported.

Respondents recognised that it can be difficult to help people with profound disabilities understand that someone has died and won't come back and euphemisms such as 'passing' and 'lost' may only exacerbate this confusion. It was felt that this practice has changed over recent years, with most learning disability services aware of the need to help people cope with their bereavements, and that they must be allowed to grieve and express their feelings. However, there are still cases where people are excluded from usual grieving processes and practices.

¹⁹<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronavirusCOVID-19relateddeathsbyethnicgroupenglandandwales/2march2020to15may2020>

it was felt to be vital that they are informed of the death in order to avoid disenfranchised grief which can cause emotional, behavioural and mental health problems for the individual and challenges for services and families supporting them.

People with learning disabilities and those who may find it more difficult to process language, such as people who are neurodiverse, may need specific interventions. However, in the context of very few specific services being available, respondents also noted the importance of ensuring people with learning disabilities don't miss out on support from standard services which if appropriately tailored could also be of value to them.

Concern was also expressed with regards to the expansion of support provided online and how this may not be effective or welcomed by some people with learning disabilities or those who are neurodiverse.

The experiences and needs of people who are LGBTQ+

Research has identified high levels of complicated grief amongst both bereaved partners of same and different gender couples, but significantly higher levels of psychological distress among same-gender bereaved partners.

²⁰Factors which have been associated with this include:

- Not being out with their social networks leading to greater isolation; feeling uncomfortable disclosing their relationship; or fearing discrimination by services
- Not knowing where to access support
- Lack of recognition or unequal treatment of their relationship and uncomfortableness from professionals talking about relationship - resulting in reduced access to bereavement support

This final point was also born out in the quantitative evidence, as it was found that those from an LGBTQ+ background were nearly twice as likely than those from a cisgender, heterosexual background to say that fearing professional emotional support would not provide the help they needed was an obstacle to accessing desired support (see Appendix E for full statistics).

The experiences and needs of prisoners

Respondents highlighted that many bereaved prisoners (including those bereaved following the death of another inmate) faced an environment in which it was difficult for them to express their grief and display vulnerability. Where bereavements occurred in prisons, the prisoner may not be able to attend the funeral or would require an escort if they did, which was associated with shame and segregation. Respondents also highlighted limited access to bereavement support services.

Respondents noted that people sometimes ended up in prison following family breakdowns, homelessness and substance misuse triggered by bereavement. Where a death was associated with a relationship which had been abusive this also made it particularly difficult to deal with bereavement.

Support which meets the needs of underserved communities

There are many barriers to meeting the needs of minority ethnic communities within the UK, as well as other underserved groups such as people with disabilities, homeless people, prisoners LGBTQ+ people. However, there were some examples given in the oral evidence of existing good practise in support for these groups. These are detailed below;

Examples of good practice improving support to Black, Asian and ethnic minority communities include:

- Cultural awareness training developed by the BAMEStream/Ubele Initiative enabling people to learn about end-of-life, funerals and rituals of other cultures
- Culturally competent support for people struggling with bereavement provided by BAMEStream. Support is language sensitive: providing support in the mother-tongue, and using the right language to reach the right audience, including young people.
- The Bayo platform hosted by Ubele Initiative provides a directory of organisations that support young black and brown people with mental health challenges, and also a library of resources developed by people from

Examples of services working with marginalised and homeless people:

- The One25 charity supports sex-workers following a death. The charity proactively and sensitively supports members of the community following a death, holding memorials, provides advocacy and help finding out about friends etc
- Hospice UK grant funded a partnership project to create holistic care package for homeless people, including bereavement support. The service would proactively find people who missed appointments and provide support on the streets when needed, it also found accessible community space to work in, and worked more flexibly than in a normal bereavement service.

Examples of practice to support people with learning disabilities:

- MacIntyre Care- a learning disability service provider-provides training to staff in talking about death and dying, with involvement from people with learning disabilities.
- Picture story resources such as Books Beyond Words can be effective at helping people understand death and talk about feelings, including grief, if used appropriately by a supporter with the person.
- The Palliative Care for People with Learning Disabilities Network have released a series of webinars, including bereavement, that health care professionals may find useful.

Examples of practice to support people in prisons:

- A local hospice developed an intervention to improve the bereavement support available in a nearby open prison. The project aimed to normalise grief and enable people to develop their coping skills and strategies. A bereavement support group was set up and provided fortnightly individual counselling sessions. It also trained peer-mentors and staff to enable them to provide support when bereavement project workers weren't working there

Improving support for currently underserved communities

As we have seen, some groups face particular barriers to accessing the support that they need. Support needs to be appropriate for diverse communities across levels of literacy, cognitive ability, gender, communication styles, beliefs about death, dying, bereavement and help-seeking, and confidence in health and social care organisations and

systems. Organisations and communities must strive to reduce digital exclusion to address some of the challenges experienced in isolated communities.

We must build trust and greater collaboration between established services and different faith or community groups, charities and others, in order to ensure that access to bereavement support is equitable.

“Make sure it is a safe environment and accessible for everyone to go to.” (16/17 year old)

“How we handle bereavement (whether that is beliefs over what has happened, how to maintain a connection to the deceased or practical arrangements before/during /after death) is heavily influenced by our religious/cultural beliefs and therefore bereavement support needs to reflect this.” (Children’s bereavement support organisation)

Within responses received by the commission, several suggestions were put forward regarding how to reduce the inequity that we know exists in access to emotional support services to cope with a bereavement. The first concerned developing and delivering targeted initiatives to address diversity and inclusivity within both the people delivering support and in those accessing them. It was recommended that in order to be impactful, these must be codesigned with the communities that they are intending to serve. Alongside this, initiatives are needed to raise awareness of existing services among groups with less equal access. There is also a need to raise the profile of these services and share widely the beneficial impact that they can have for individuals, families and communities.

Underpinning any new initiative is the need to establish trust when supporting people from diverse communities. Respondents felt that in order to facilitate engagement with a service, people need to feel reflected, welcome and accepted. The early involvement of a range of people from different backgrounds within the design and development of services could be a welcome first step in moving towards this goal.

To deliver more inclusive services, there is also a need to ensure that staff within organisations have the skills and knowledge to work in a person-centred way and avoid pursuing a one-size-fits-all approach. This up-skilling workforces will require investment in training to inform staff about the needs of different groups, the impact of different losses and different forms of disenfranchised grief and trauma.

Recommendations for racially and culturally minoritised communities

Respondents agreed that there was an urgent need to increase the cultural competence and knowledge of existing staff and volunteers including knowledge of different rituals, recognition of the close kinship ties that exist outside of immediate family in some minority communities and enabling access to support for those often not considered ‘direct’ family.

Recruiting a more diverse workforce, and providing support in different languages and for different religious and cultural groups would both help people from different communities to feel seen and accepted by services, and also widen staff awareness of different cultures, religions, practices and values. As well as reflecting diversity within their workforce, respondents to the commission felt that organisations also need to ensure that their imagery, resources and materials for the public also represent a diverse range of people and experiences.

Different cultures and traditions around death, dying and bereavement need to be known, discussed and accepted. Existing services should be open to developing new forms of delivery and – in order to do so - encouraged to work in partnership with different groups across the community, and a wide range of different people with lived experience of dying, death and bereavement.

There also needs to be better support for and resourcing of services led by, and within, those communities which are most poorly served.

“If bereavement groups could be set up within communities and led by community leaders or those who speak the language and fully understand the culture/faith then they will be much more effective.” (Child bereavement support organisation)

“As we reach out as a sector much more become much more proactive I think we acknowledge that there is a huge amount of work to do to learn actually, about what communities need about where support is best driven from and not to make an assumption that actually its best delivered by the organisations that have always delivered bereavement support. I think partnership is going to be incredibly critical.” (Child bereavement support organisation)

The need for embedding the routine collection of data around faith and ethnicity of service users will also be imperative to ensure that services understand who they are, and are not, reaching.

Recommendations for supporting people with learning disabilities:

Organisational respondents emphasised how providing appropriately tailored support for people with learning disabilities depends on careful assessment of needs by trained and competent staff and volunteers.

“Not only is robust assessment at the outset imperative, but ongoing assessment of evolving and changing need as support progresses is essential.” (Children’s bereavement support organisation)

Further suggestions for improving care for people with learning disabilities and their families included supporting staff and families to talk openly about death and dying with people with learning disabilities – supporting them through any emotions or challenges they experience – and including people with learning disabilities in rituals and visitation of relatives who are dying.

It was suggested that training around death, dying, and bereavement should be compulsory for learning disability service staff to equip them with the skills and knowledge needed to support people experiencing a bereavement. Similarly, palliative care services, who may have limited experience supporting people with learning disabilities also need support to understand how to adapt their services to offer the best possible care.

Recommendations for better supporting people experiencing homelessness:

People experiencing homelessness are disproportionately likely to suffer from mental ill health and substance misuse, which may then be exacerbated by the distress caused by the loss of somebody close to them. In order to respond to this, professionals providing support to homeless people following a bereavement, need to be highly skilled, flexible, and trauma-informed.

Multi-agency working, training on and provision of trauma informed care and flexible approaches to providing support will be crucial in improving access to bereavement support for this group. Evidencing the impact or success of services and interventions also needs consideration as traditional Key Performance Indicators (KPIs) (such as number of sessions attended) may not be the best measure of success for supporting this group. Person level, rather than system level outcomes may be more appropriate measures of success.

There is growing work around connecting palliative care services with those that support people experiencing homelessness. Marie Curie and Pathway, in collaboration with other health and social care agencies have established a multi-professional nationwide ECHO network to promote shared learning and professional connections to improve the care and support that people experiencing homelessness receive towards the end of their life and also in bereavement.

Improving support for people in prisons:

There is much to be done to improve bereavement support for prisoners. Work that aims to normalise grief and enable people to develop own coping skills and strategies should be supported, alongside training and support for people that work in prisons who may also need bereavement support. The use of peer-mentors should be encouraged to support those who have been bereaved in prison.

Recommendations for better supporting LGBTQ communities:

All bereavement services should be cognisant of, and able to meet the needs of, LGBTQ+ communities. Positive, proactive approaches to inclusion – including the use of inclusive language - should be taken to address concerns around discrimination, helping to enable trusting relationships and to make sure people feel comfortable to share who they are.

Exemplar services exist which specifically support LGBTQ+ communities, but they are few and far between and have been vulnerable to funding cuts. Respondents noted that not everyone who is LGBTQ+ will want LGBTQ+ specific services, but many will want to connect with those with similar experiences to their own, which may include other bereaved LGBTQ+ people.

Part C- Delivering optimal and appropriate support which meets the needs of local and national populations

The first two sections considered some of the main challenges affecting access to bereavement support services, in general and with regard to the needs and experiences of under-served groups. However, individual and organisational respondents also recognized that some of the main barriers preventing timely access to appropriate support are outside of the control of individual services and reflect a lack of coordination and adequate funding in the sector more generally. Organisations, in particular, 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 appropriate and optimal services

Squeezed from both sides: lack of funding and increased demand

Individual and organisational respondents attributed the reported lack of availability of emotional support services to the inadequacy of funding. Organisations pointed out that the NHS is over stretched and does not have capacity to provide emotional and psychological bereavement support to everyone who needs it; and this puts the onus on the voluntary sector.

Organisations highlighted that statutory funding for bereavement support across the sector is rare. There was a sense that decision makers don't understand the potential preventative value of bereavement support. Lack of statutory funding means a reliance on charitable funding and while it is hard to get a full picture of bereavement support funding, there is evidence of a 'postcode lottery' of support.

*“More funding as I couldn't access [support] due to funding lack”
(16/17 year old)*

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)

Even where statutory funding was available, it was often only short-term. Uncertainty of funding impacts the sustainability of services and results in a short-term focus. A short-term focus means organisations cannot focus on service improvement or invest in staff e.g. funding up-to-date staff training. It can also be problematic to fund short-term initiatives which introduce support which then disappears when the funding finishes. In addition, it is not always cost-effective to fund short-term projects given the amount of time spent writing grant applications, meaning small community-based organisations are less likely to receive it.

*“Most is delivered by third sector with funding not guaranteed from one year to the next.”
(Children’s bereavement support organisation)*

“Local authorities and public health budgets seldom allocate much financial support to children's bereavement support, whilst CAMHS signposts children to our service, saving public money, we are not reciprocally funded. It's all ad hoc and not sustainable.” (Children’s bereavement organisation)

A lack of statutory funding means a reliance on charitable funding. Organisations highlighted that the continuous, significant effort that organisations have to put into fundraising to maintain as well as develop services is a major issue. The pressure to fundraise and deliver services also limited services’ capacity to advocate more broadly for support.

“Funding for bereavement support is sparse and seems to be borne by the charitable sector. This may well prove unsustainable and also conveys the idea once more that bereavements are not to be spoken of and those who are bereaved should just carry on”. (Children’s bereavement support organisation)

“Funding for bereavement support is patchy with very few "bereavement" specific sources of funding for organisations.” (Children’s bereavement support organisation)

Respondents highlighted that the pandemic worsened the funding situation, as some fundraising activities became impossible. Some organisational respondents to the call for evidence reflected that emergency funding hadn’t reached them going instead to national organisations with more prominence.

“We have always been supported by strong community fundraising by communities impacted by sudden bereavement but through the pandemic we have seen a very significant fall in fundraising. This has happened at the same time as demand from suddenly bereaved families has increased by 39%.” – organisational respondent

Alongside inadequate resourcing, services also noted that they were simultaneously being squeezed by increasing demand.

“As more people become aware of the benefits of accessing support demand increases. If our direction of travel is to increase awareness of death and the benefits of accessing support we will need to increase capacity to meet the need.” (Children’s bereavement support organisation)

Rationing support

The outcome of this mismatch of funding and demand was a rationing of support, for example limiting the types of bereavements which could be supported, or the amount of support provided, or requiring people to wait a long time for help. Services acknowledged that these constraints prevented person-centred approaches, and that rationing could in turn increase the complexity of grief.

“They were very good at first; but like so many of these smaller charities, they simply didn't have the resources or personnel to regularly meet with him.” (Parent of 5-12 year old)

“As it was her Uncle who died there is no support for her.” (Parent of 5-12 year old)

“There is no support for children who have no link to a hospital or hospice. My husband died in a road collision and there is no free therapy anywhere for my children” (Parent of 5-12 year old)

“There is never enough for the needs, we end up rationing what we can deliver.” (Children’s bereavement support organisation)

“Funding is never enough. Bereavement is a constant even if numbers vary. Not enough financial investment in services such as counselling leads to longer waiting lists and more grief turning into more complex grief.” (Children’s bereavement support organisation)

“We are worried about waiting times for access to services all of that is something that the sector needs to address and needs support to build capacity I think to enable it to come through some of these challenges”(Children’s bereavement support organisation)

Lack of coordination between services

Despite some examples of good practice, there was felt to be a general lack of coordination prioritisation and strategic orientation between services, across the four nations. Insufficient funding was cited as a key barrier to partnership development and service coordination by many organisational respondents.

Improving services: commissioning, quality and coordination

A number of different suggestions and recommendations were made for improving the provision and delivery of formal bereavement support. These included increased funding and commissioning of services; improved monitoring, evaluation and needs assessment practices and improving the local and national coordination of statutory and voluntary services within the bereavement sector.

Increased statutory provision and funding for the bereavement sector

As evidenced in the previous section, many respondents were frustrated with the difficulties encountered in trying to access support, including long waiting lists. Respondents felt that more bereavement support should be provided by the NHS to tackle the backlog in support needed.

“I am surprised the only bereavement support available to people is via bereavement charities like CRUSE and not NHS or state-run organisations especially with the increased awareness around mental health these days. I have felt suicidal many times during my grief - my GP suggested IAPT, CRUSE, the Samaritans, getting things in my diary and volunteering as an aid to distract me from my grief. I believe the waiting list for CRUSE is almost a year so I didn't apply.” - Woman in her 40s whose husband died of a stroke (England)

*“Most of the support services seem to rely on volunteers, and consequently there are long waiting lists. The Mental Health support given from the NHS should be better funded, and include bereavement support, which it didn't appear to do, at the time of my late husband's passing.”
Transgender Woman in her 70s whose husband died of cancer (England)*

As part of a coordinated approach to commissioning, respondents argued that **more funding is needed for bereavement services** – which must be provided in a sustainable way and be equitably allocated to groups working with diverse communities. Organisations also argued for ring-fencing funding for bereavement and end of life care, to ensure that money reached these key – and often under prioritised - service areas.

Some respondents suggested that where there had been uplifted funding provided during the pandemic – for example, for suicide bereavement support - this should be maintained.

“In order to meet the needs of bereaved individuals, it would be beneficial for the government to provide CCG's with increased funding to commission and support research for services needed by specific communities. This should be a priority of government strategic planning and expenditure; to ensure access to sustainable support. Currently services across England heavily rely on fundraising made by the voluntary sector; in order to meet the needs of individuals experiencing bereavement, services must be sustainably funded.” – organisational respondent

In addition to supporting core service delivery, respondents highlighted that more funding is also needed for research, evaluation, quality improvement and coordination (including through the development of local bereavement networks.)

Monitoring, evaluation and standards -improving the quality and responsiveness of services

A strong theme throughout the organisational evidence was the desire for greater mapping, monitoring and evaluation of support services, with a perception that these practices are currently inconsistent across the sector.

Consistent monitoring and evaluation is needed to help organisations understand the impact of the support they are providing, and to adjust where necessary.

“Less paperwork would be great! but it is also a vital part to the understanding, growing and supporting process.” (Children’s bereavement support organisation)

“A follow up phone call needs to be provided to the families to ensure the support is okay for them.”

“Better use of common assessment tools (such as the Adult Attitude to Grief Scale and the Child Bereavement Service Questionnaire) would facilitate better assessment of need with organisations ‘speaking the same language’ and consistently using the same measures. Practitioners trained in the use of validated measures to assess aspects of vulnerability and resilience can give consistency in assessment...as well as providing robust outcome data.” (Children’s bereavement support organisation).

More research was also felt to be needed into the effectiveness of bereavement services and the value of the sector. Respondents argued that the capacity and skills to undertake monitoring and evaluation of services should be built into organisational infrastructures. Better practice in this area would help make the case to commissioners and funders – at both a local and national level - about the value of these services. Some participating organisations suggested there should be standards for both emotional and practical bereavement support – including a national framework for referral and assessment.

Mapping of local needs and provision

Organisations highlighted that evidence is missing about the extent and nature of bereavement support needs and provision in different areas and amongst different communities.

“I think in terms of national government there is a huge issue for us which is about data. We don’t know enough about how many children and young people are experiencing grief and bereavement. We as a sector have long campaigned for data capture at death registration” (Children’s bereavement support organisation)

In order to address this, respondents suggested that national or local level mapping of service provision and need should be undertaken and used to inform development and commissioning of services. For example, one respondent suggested that a mapping exercise could be conducted in Scotland to identify existing bereavement support that’s available and being delivered in the statutory and third sectors and to identify the gaps of training and resource, then mapped against the different levels of need.

Better coordination and collaboration between services- towards a public health approach

In the oral and organisational evidence, a “public health” approach to providing bereavement support was advocated, looking across the whole system of support, rather than addressing any individual aspect. Respondents reflected that this would mean:

- Focussing on the conditions in which people can experience “good grief”, and how we prevent more complex grief
- Promoting resilience and changing cultural attitudes to grief and bereavement, so more support is available in everyday society and social interactions.
- Improving the ability to recognise and support normal grieving and to identify abnormal grief and when people need additional, more intensive support

Better collaboration and coordination between local services was felt to be imperative to improving support for local bereaved population, across whole systems and networks of support. Better collaboration between services in local areas would mean that ‘no one falls through the gap’ and gets the support most appropriate to their needs. There is a requirement for a ‘mosaic’ of support from different people and organisations with different skill-sets. It is crucial that people are able to be supported by the right people, with the right skills when the time is right for them.

Local coordination and collaboration across statutory and voluntary sector services

The evidence identified some areas of good practice where there was effective local coordination. One example of such coordination was signposting and referral pathways between services. This was often the case when people had a supportive GP who could signpost them to other bereavement specific services.

“My GP was very understanding and helpful. She really listened to me via several phone calls and I am grateful to her for being there for me and reassuring me in my darkest moments and directing me towards external support. She referred me to a local bereavement support charity and prescribed medication for me to help me sleep and for depression” - Woman in her 50s whose husband died of a heart attack (England)

“Mental health support worker at GP surgery was amazing they supported me for a year and I would have regular phone calls with them. After speaking to a different doctor they moved me onto the mental health support worker which I'm very grateful for. He was really good at letting me know what services there were locally and that they had a drop-in centre near me that I could access.” - Woman in her 40s whose husband died by suicide (England)

Organisations also emphasised the benefits when care is joined up and involved collaboration between multiple professionals e.g. involving funeral directors, chaplains etc. This could facilitate a more holistic offer of emotional support and often included advice on practical matters. There was some reflection that the pandemic had improved cross-sector collaboration.

Respondents suggested that local partnerships should include:

- Funeral directors
- Health boards/Primary Care
- Bereavement support providers
- Social services
- The third sector
- Local authorities
- Faith and community groups

Effective local collaboration could help to provide a holistic and far-reaching support network for bereaved people, with improved information sharing, and referral between services. It was felt that organisations should be clear about exactly what they offer within a local network of services, and be prepared to refer and signpost on when necessary.

“It would also be beneficial to have organisations working collaboratively to offer initial assessments that determine what kind of support service is most appropriate for the bereaved person, especially in relation to the pyramid model mentioned above (used to distinguish levels of intervention based on levels of need).” (Children’s bereavement support organisation)

“Care pathway development leading to smooth, quick and easy two-way referral processes and closer working/liaison with mental health services e.g. bereavement link workers in adult and child mental health services, and trauma services can help ensure people’s needs are appropriately assessed.” (Child bereavement support organisation)

“There are lots of bereavement services out there, they should be clear on their websites who they support, and share other services for other people on their sites.” (Children’s bereavement support organisation)

There was discussion on the plethora of support available for bereavement in Wales. This is both a positive thing in that people have a variety of support available to choose what fits their needs best, but it can also make the system confusing and complex to navigate. Organisations highlighted the need to simplify the network of support and make it easier to understand and access, without limiting choice and flexibility.

Respondents felt that supporting healthcare teams and GPs to refer directly into bereavement services might help to improve access.

“If GPs could signpost and approve support directly, this would be better.” – organisational respondent

Databases of locally and nationally available support

Organisations highlighted the need for accessible database of agencies that provide bereavement support, that can be accessed by bereaved people and also used for signposting by people working with the bereaved e.g. chaplains, healthcare staff, care-homes, death- registrars, GPs, funeral directors, ambulance staff.

Some respondents suggested it would be valuable to have a single hub of information or a directory of services (like AtALoss.org), which would need to be funded, widely promoted, and kept up to date. AtALoss.org aims to provide information on local and national initiatives and enable people to find the most appropriate, available support by using filters for type of death, relationship and locality. Most of the well known national initiatives are now included but it has been more challenging trying to include information on local, peer-support and faith-based initiatives, which the project is keen to include.

Assessing and responding to individual needs; developing well-coordinated local pathways

It was suggested that a standardised pathway into support for anyone experiencing a bereavement could be one way of helping to ensure the right support is offered at the right time. However, some respondents also noted the importance of different pathways related to particular types of loss or requirement, in recognition of the different support that may be needed.

“I felt there was a lack of understanding that a suicide is a complicated death and the grief around that is complicated and hard to cope with and I was grieving in a pandemic.” - A women in her 40s whose husband died by suicide (England)

There was a suggestion that closer working between mental health, bereavement and voluntary and statutory services would be needed to ensure people can access timely and appropriate support from whichever service would meet their needs. This may involve the co-location of bereavement services within mental health services and vice-versa so that people can be immediately directed to support following triage.

Improving referral and assessment practices for children and young people

There was recognition that children and young people required different pathways into emotional support to cope with a bereavement. Part of this would require **training within organisations that encounter families, children and young people with regards to referrals into services**

In addition, it was highlighted that any triaging or assessment that was undertaken regarding needs for bereavement support should be trauma-informed to address the potential complexity and longer-term impact of loss during early life.

“Widespread bereavement awareness training and education within workplaces and organisations will help to highlight the needs of the bereaved. This, in turn, should help the assessment of their needs and ensure that the bereaved are adequately signposted or referred to suitable support services.” (Children’s bereavement support organisation)

“Given the increasing complexity of referrals, training in trauma-informed assessment will be increasingly important in the sector to ensure people get the right type of support at the right time.” (Child bereavement support organisation)

Linked to the issues of complexity and longer-term impact, it is essential that organisations have the capacity, knowledge and willingness to identify when and how to refer children and young people to other services when they are not able to meet that person’s emotional needs.

“It is also imperative that practitioners are assessing through their supervision whether they are the most appropriate person to be providing the support as needs change.” (Children’s bereavement support organisation)

Organisational respondents highlighted problems where children who have experienced a bereavement are referred to voluntary sector bereavement services without a mental health assessment. This resulted in some children not receiving the specialist children and young people’s mental health services (CYPMHS) support that they need. At the same time, they highlighted a lack of bereavement skills within CYMHS for supporting children with mental health needs who are bereaved. To respond to this it was felt important for services to be able to recognise need for mental health support in children, and for CYMHS professionals to be trained in bereavement.

It was also suggested that for bereaved children and young people, organisations may consider implementing assigned key workers for each child or family to help them navigate support services.

“we have a Named Team Member for a bereaved family and it is their role to check in regularly with a bereaved family, advise of services and coordinate the other professionals in the organisation to respond to need. A service or individual who can coordinate this for a bereaved family out in the community could be invaluable” (Children’s bereavement support organisation)

National and regional coordination of services

Participants reflected that coordination of services is also needed at national level. The National Bereavement Alliance and Childhood Bereavement Network were cited as examples of valuable sector coordination across the UK.

Some participants suggested introducing a National Framework for commissioning bereavement support services in each UK Nation, which would put an emphasis on collaboration. Each of the UK nations is in a slightly different position as regards progress on development of a national approach to coordinating bereavement support.

Wales

A new National Framework for Bereavement Care in Wales was launched in October 2021. It is hoped that the new framework will improve coordination of services in Wales, with a clear and universal understanding of what support should be available and where. The framework is supported by a steering group to guide planning, commissioning and delivery of bereavement care. It seeks to support commissioners and providers to understand their responsibilities to ensure the provision of equitable and timely access to high-quality bereavement support to the local population.

Respondents felt that the Framework must deliver on its commitments and the Welsh Government must consider a fully cross-departmental bereavement strategy. The close-knit nature of Wales and preference for a collaborative approach was seen as providing an advantage in pursuing more partnership-based ways of working in the bereavement space.

Northern Ireland

In Northern Ireland, there was felt to be a need for a Bereavement Network to work across all sectors to develop a 10 Year Strategic Plan, including a mapping and scoping exercise which can inform the commissioning of future services. The recently formed Bereavement Network is working collaboratively to develop a 10 Year Strategic Plan. The network gives access to staff training, and a website hub for finding information.

Scotland

In Scotland a Scottish Bereavement Charter was set up out of frustration at the lack of progress in bereavement support over the last decade, to set out national principles for bereavement support in the nation. Respondents argued that the National Bereavement Charter in Scotland must be further funded and rolled out and the palliative care strategy should be broadened to incorporate bereavement policy, and recognise the close relationship between end of life care and bereavement support. Another respondent suggested a Bereavement Reference Group could be established in Scotland. A suggestion was also made that bereavement support or signposting is brought within the remit of the new National Care Service in Scotland.

England

Respondents from England highlighted the need for a National Bereavement Strategy for England –which should set out leadership and responsibilities around bereavement at both a national and local level. One respondent from England reflected that the bereavement minister needed to be more accessible to the bereavement sector and provide more support.

As bereavement currently sits across a range of government departments, and has no single area of responsibility, respondents argued there is a need for clear leadership in England and a way that organisations and people can be brought together to share resources and ideas at a national level, and to support the funding and delivery of consistent and high-quality bereavement care.

“We need to join up thinking across Whitehall departments, in all areas of policy making and service planning because, as these examples demonstrate, grief is not a standalone issue.” – organisational respondent

Learning from the pandemic and responding to mass-bereavement events

Finally, the commission heard the importance of learning from the pandemic in terms of supporting coordination at both the local and national level. Respondents highlighted that collaboration will be particularly important in preparation for future mass bereavement events – in order to respond more effectively in the future, there will need to be improved support pathways and timescales for access to services. Local and regional resilience forums can develop plans for supporting bereavement in future mass bereavement events. There was a suggestion that there should also be a formal bereavement lead role within ICSs:

“[T]here should be a bereavement lead at ICS level who is responsible for engaging with local communities to assess local support needs, and commission services accordingly.” – organisational respondent

In case of future mass bereavement events, Governments should be prepared to work closely with national and local community organisations, charities and faith groups to coordinate responses that meet the bereavement support needs of all communities – with an emphasis on ensuring support reaches those who are most poorly served.

The work to set up such coordination cannot happen overnight. To prepare for future mass bereavement events, it is crucial that investment and leadership around service coordination starts now.

Conclusion and Recommendations

The evidence presented in this chapter has highlighted the value of appropriate formal bereavement support to those who need it, but also identified a wide range of challenges that individuals face in accessing it, and services face in delivering effective support.

These include lack of available support and knowledge of how to access it, insufficient funding, lack of coordination between services and sectors, and lack of evaluation and research which is needed to ensure quality and optimal service delivery. Respondents also highlighted profound inequities that exist in bereavement support, with many groups being very poorly served.

There is a clear need for increased statutory funding, greater collaboration and coordination and increased focus on 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 both now and in the future.

Key recommendations from the Commission:

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 emotional bereavement support, governments in each UK nation must invest 79p annually per person in the population to transform 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 new approaches to signposting support and piloting the feasibility and effectiveness of and 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 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.
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 other 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; and that 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 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. 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.

However, in addition to significant shortcomings in the provision 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.

The eight principles for change set out our vision of how to improve support through a bereavement.

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:

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, prioritising under-served and minoritised 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, 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 should be required to provide opportunities for children 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:

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 schools and other education settings should be required to have a bereavement policy including staff training, and a process for supporting a bereaved child 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:

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

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:

Recommendations:

- 1 The UK Government 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:

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

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:

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)

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:

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 National Insurance contributions due to sickness or disability
 - » 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, accessible to and appropriate for all who need it. We are therefore making the following recommendations:

Recommendations:

- 1** Bereavement services that provide emotional support (including 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 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 and improving bereavement support for 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.

Identifying the changes that are needed is just the start. If we want to improve the support for bereaved children, young people, people, families and communities, Governments, organisations across the public, private and third sectors, faith communities, 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, believe that the vision set out in this report is achievable. They look forward to working with all those willing to help to transform and improve the support for anyone affected by bereavement across the UK.

You can find out more about the Commission's work, and get in touch at <https://bereavementcommission.org.uk/>

Appendices

Appendix A: Full list of recommendations

<p>...I am supported by my family, my friends and the communities around me.</p>	<p>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, prioritising under-served 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.</p> <p><i>These initiatives will be led by networks of charities, faith groups, community-based organisations, compassionate communities, academics and health and social care providers, co-produced with people with lived experience.</i></p> <p>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</p>
<p>...I am sensitively supported by my school, college or workplace during my bereavement.</p>	<p>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, with specific guidance on support for those who experience death and bereavement in the course of their work, written in consultation with all relevant stakeholders in the public, private and third sectors.</p> <p>Statutory bereavement leave and pay entitlement of 2 weeks must be extended to encompass all close relationships</p> <p>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</p>
<p>...I feel well supported before and during the death and feel confident that my relative received appropriate and compassionate care</p>	<p>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</p> <p>Governments across the UK must ensure that there is sustainable funding and effective delivery of palliative care services</p> <p>To ensure an integrated approach to delivery of care before, during and after the death of someone, Governments across the UK must ensure that palliative and end of life care strategies are effectively linked to bereavement support strategies</p>
	<p>Governments across the UK must legislate so that people can choose whether to register a death in person or online</p>

<p>...the things I must do after a death are simple and straightforward</p>	<p>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</p>
<p>... the professionals I am in contact with at all stages through my bereavement are compassionate and helpful</p>	<p>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</p>
<p>...I have access to an affordable and meaningful funeral</p>	<p>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</p>
<p>...I feel secure in my home and have the right financial support.</p>	<p>New regulations must be created setting out minimum standards for public health funerals</p>
<p>...I feel secure in my home and have the right financial support.</p>	<p>Funeral Expenses Payment must be extended to currently excluded groups including students</p>
<p>...I feel secure in my home and have the right financial support.</p>	<p>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).</p>
<p>...I feel secure in my home and have the right financial support.</p>	<p>Entitlements to financial support following a bereavement must be extended to key groups including:</p> <ul style="list-style-type: none"> - 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
<p>...I feel secure in my home and have the right financial support.</p>	<p>Financial support following a bereavement must be extended beyond current time limits:</p> <ul style="list-style-type: none"> - 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)
<p>...I feel secure in my home and have the right financial support.</p>	<p>All benefits for bereaved people must be up-rated annually in line with inflation in all four nations</p>
<p>...I can easily find and access the right emotional bereavement support that</p>	<p>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.</p>
<p>...I can easily find and access the right emotional bereavement support that</p>	<p>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</p>

recognises my needs and circumstances	<p>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</p> <p>In order that everyone has access to good and appropriate bereavement support, each of the UK governments must deliver a ringfenced package of funding for the transformation of bereavement support over the coming 5 years, with a particular focus on better supporting Black, Asian and ethnic minority communities, and other people and groups who are currently poorly served. As well as service delivery, it must cover:</p> <ul style="list-style-type: none"> • quality improvement including training and tailoring of support <ul style="list-style-type: none"> • 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 new approaches to signposting support and piloting the feasibility and effectiveness of and offering bereavement support proactively to specific underserved and vulnerable groups. <p>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</p> <p>Governments in all four nations 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.</p>
Scotland specific recommendations	<p>The National Bereavement Charter must be funded to mainstream its work.</p> <p>The new National Care Service must commission bereavement support and signposting.</p>
<p>In order to deliver all of the above recommendations, each UK Government must establish and deliver a cross-departmental strategy for bereavement in partnership with bereaved people. This must:</p> <ul style="list-style-type: none"> • encompass all aspects of public policy affecting bereaved people • involve the voice 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 	

Appendix B: Impact of the COVID-19 pandemic

The UK Commission on Bereavement acknowledges the scale and impact of the COVID-19 pandemic on the United Kingdom, including those who were bereaved during this time. Members of the Commission's steering group led a national academic study of bereavement during the pandemic which has fed into this report. ²¹

Papers published so far include:

- Harrop E. et al. *Support needs and barriers to accessing support: Baseline results of a mixed methods national survey of people bereaved during the COVID-19 pandemic*. Palliative Medicine, Oct 2021
- Selman LE et al *"Sadly I think we are sort of still quite white, middle-class really" – Inequities in access to bereavement support: Findings from a mixed methods study*, Palliative Medicine, in press
- Selman LE. Et al *Risk factors associated with poorer experiences of end-of-life care and challenges in early bereavement: Results of a national online survey of people bereaved during the COVID-19 pandemic*. Palliative Medicine, February 2022
- Harrop et al. *Parental perspectives on the grief and support needs of children and young people bereaved during the COVID-19 pandemic: Qualitative findings from a national survey*. [preprint] ²²
- Torrens-Burton et al. *"It was brutal. It still is": A qualitative analysis of the challenges of bereavement during the COVID-19 pandemic reported in two national surveys*. Palliative Care and Social Practice 16, 1-17 (2022).
- Selman et al. *Factors associated with higher levels of grief and support needs among people bereaved during the pandemic: Results from a national online survey*. [preprint]²³

Evidence from individuals and organisations gathered by the Commission confirmed that the pandemic had profound and largely negative impacts on people's experiences of grief and their support needs, increasing feelings of pain, isolation, and trauma.

Without the right support, there will be long term consequences for people bereaved during COVID-19, across all elements of public and private life.

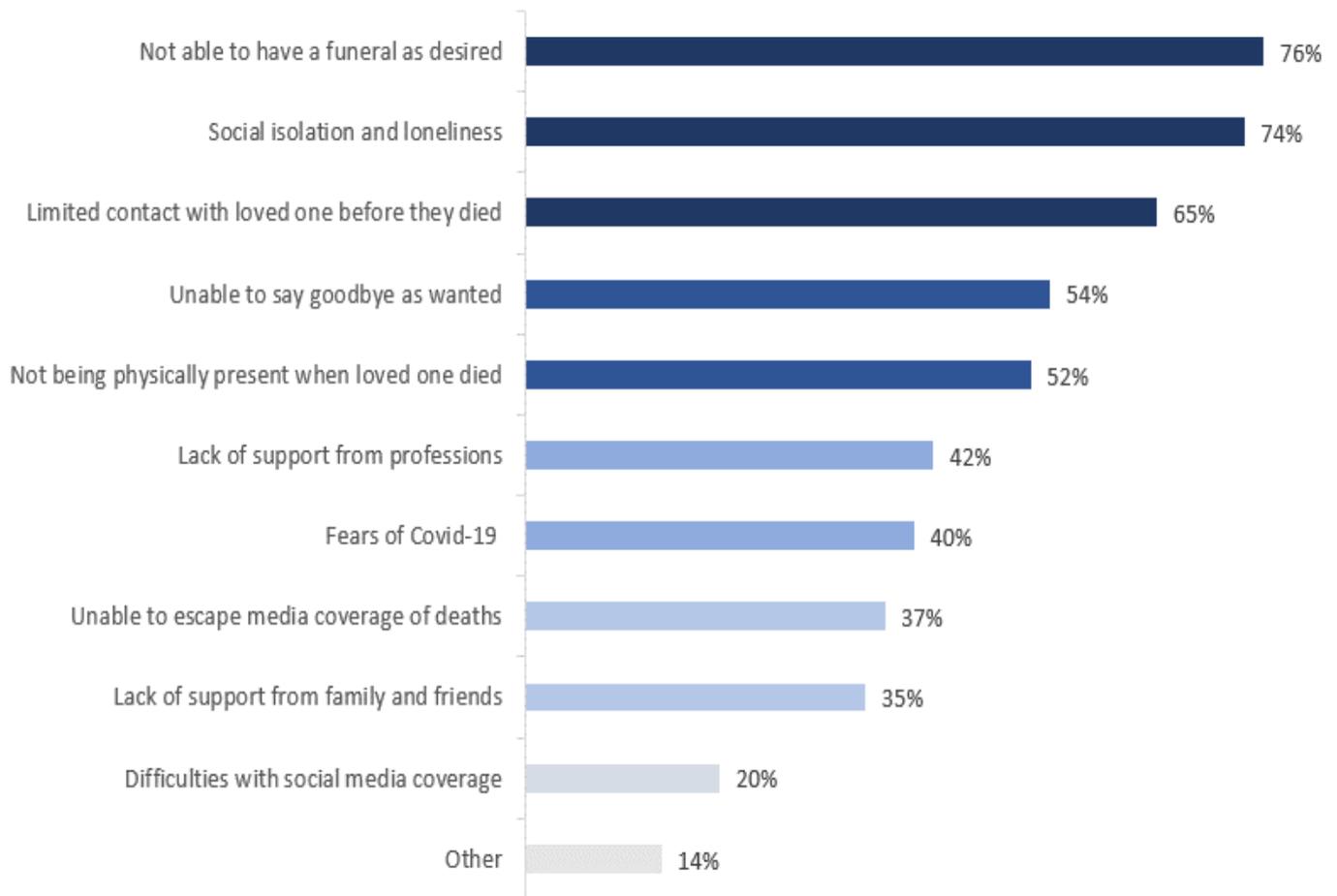
The scale of the disruption

Over 60% of respondents to the Commission indicated they were bereaved during the pandemic. This graphic shows the disruption to normal grieving.

²¹ The website for the study is [COVID-19bereavement.com](https://www.covid-19bereavement.com)

²² <https://doi.org/10.1101/2021.12.06.21267238>

²³ doi: <https://doi.org/10.1101/2022.02.07.22270593>



Note: graph represents the responses from 757 adults

End of life experiences

The pandemic highlighted the gaps and inequalities of people’s experiences at the end of life, and the support they receive. Careful and supportive planning around an expected death is linked with better outcomes for bereaved individuals. This planning has been disrupted to restrictions and lockdowns. Many patients and families were unable to fulfil end of life care plans and place of care preferences due to pandemic, impacting on family bereavement experiences.

The Commission learned that

- 65% of adult respondents reported difficulties with limited contact with their loved ones
- 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

Mass bereavement and trauma

Pandemic related bereavement was associated with increased trauma, feelings of anger and anxiety, in addition to loneliness and isolation. These elements were exacerbated by bereaved people witnessing mass bereavement as a daily event, with media reports intensifying this experience.

“Reliving it every day as COVID-19 is on the news daily.” – Woman in her 40s whose husband died of COVID-19, Scotland

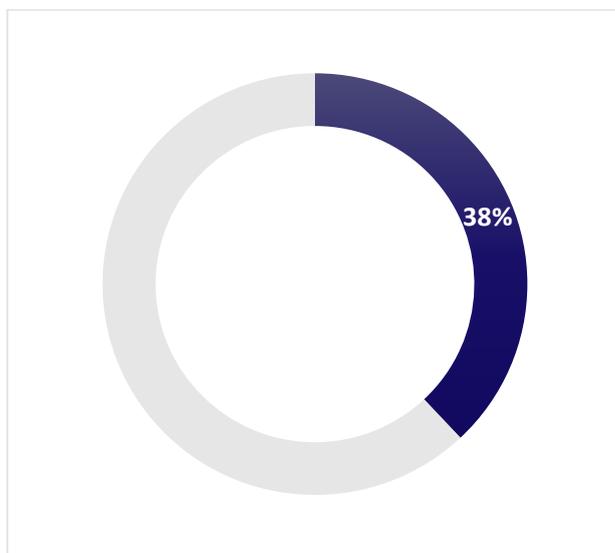
People who were bereaved during the pandemic through causes other than COVID-19 may have experienced disfranchised grief, where their bereavement was felt less important because their loved ones had not died from the virus.

“Complexity of bereaved people's presentation has increased. We are seeing more trauma. More prolonged grief, more complex grief reactions.” – organisational respondent

Lockdown restrictions

Social distancing had also had a significant impact on the way in which families and friends were able to come together to support one another in grief as they would usually do. Disruption to funerals resulting from lockdown restrictions such as delays, restrictions in numbers, and social distancing measures had a profound impact on the grieving process and celebration of life for all cultures.

74% of adults bereaved during the pandemic said they had experienced social isolation and loneliness. Over a third (35%) of adults said they had experienced difficulties with limited contact with friends and family and grieving alone.



N=1,119

The experiences of Black, Asian and ethnic minority populations

The pandemic disproportionately affected ethnic minority communities, as evidenced by ONS data: COVID-19 mortality for people of Black African or Black Caribbean ethnicity in the first half of 2020 was two to two and a half times higher than for people of White ethnicity²⁴.

Faith leaders were unable to visit dying patients and families in hospital, with traditions and obligations incomplete. Lockdown restrictions prevented those from Black, Asian or other ethnic minorities from travelling overseas to visit dying relatives or attending funerals. Family members from ‘home’ could not travel to support relatives in the United Kingdom. The bereavement experience was significantly altered for people from a wide range of backgrounds, faiths and cultures.

“Some of our local communities and not being able to carry out rituals, traditions, obligations that perhaps, well obviously would have been done in usual things, and I'm thinking from the hospital perspective around rapid release and registration, and I know that that caused a lot of difficulties for our local communities.” – oral evidence

The experiences of children and young people

²⁴<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/whyhaveblackandsouthasianpeoplebeenhithardestbyCOVID-19/2020-12-14>

The impact of the pandemic on children and young people is yet to be fully known. Children and young people have been confronted by death and dying during the pandemic in an unprecedented way, with significant media attention. Bereaved children and young people have been exposed to traumatic deaths, whether or not they were present when the person died. 77% of the children and young people we heard from said they were not able to say goodbye as they wanted with 54% saying they were not able to spend time with the person that died and 31% saying they were not with them when they died.

“I couldn't see them before they died because of COVID-19.” – 5-12 year old

“Bereaved children and families have also struggled with increased isolation, prolonging the most difficult phases of grief.” – Children's bereavement support organisation

Lockdown and social restrictions meant that bereaved children and young people have been isolated with other grieving family members. 46% of young people said they had difficulties relating to the lack of support from family and friends. The impact of school closures has also been felt. A further 31% had been affected by periods of school or college closure. Being out of school had denied children and young people a usual routine and opportunity for support. By the time they returned to school, their bereavement might not be seen as 'recent' and was therefore less likely to result in support.

Pressures had been particularly acute for children and families already in disadvantaged circumstances.

“For many families living in poverty this is a tough time as they struggle to home-school, often without the appropriate technology and in overcrowded living conditions . The stresses and strains cannot be under estimated.” – Children's bereavement support organisation

Some organisations noted that the full impact of being bereaved during the pandemic on children and young people is unknown, expressing concern about the possibility of delayed grief and delayed trauma on children and young people.

“We feel that there is a very long tail to this. We don't really know what the impact will be on children and young people...” – Children's bereavement support organisation

[Accessing support](#)

The pandemic has highlighted and intensified many of the known barriers to accessing services: unavailability of services, lack of knowledge or understanding of support, feeling uncomfortable seeking help. Only a third of the bereaved research participants had been given information about bereavement services following the death. Specific challenges included:

- technological barriers and concerns over accessing support online
- feelings unentitled to support at time of crisis
- a perception that generic support cannot adequately address their crisis-specific experiences and needs.

[Positive responses to the pandemic](#)

The pandemic has exposed a whole generation of children to death, dying and bereavement, and this presents society an opportunity to change the conversation around this important topic. Organisations talked about the value of a national dialogue around bereavement, supported by awareness raising campaigns.

Responses to the pandemic include an online death registration process which some found easier, both logistically and emotionally. However, not everybody had online access. Organisations highlighted that rapid decision making, and adaption and use of technological resources to support service delivery was welcome.

Recommendations

The Commission agreed that support for grief education, including supporting the public's awareness of death, dying and bereavement is critical. This is supported by a further recommendation for appropriate bereavement and trauma informed training for those who come into contact with the bereaved, including but not limited to health care professionals, and customer service professionals.

The Commission is also calling for specific changes to the death registration process, clarification from governments about public health funerals and learning from this pandemic to be applied to future response strategies.

Appendix C: Evidence on Inequalities

Inequalities in bereavement experiences and support

The Commission acknowledges that significant groups of UK citizens are under-served in bereavement support. Evidence highlighted that bereavement services do not reach all groups and communities who may benefit from their services. Those who identify as Black, Asian or another ethnic minority can struggle to find support that culturally sensitive and tailored to their needs. Those who identify as non-binary, trans or are a member of the LGBTQI+ community can also experience disenfranchised grief. There are people who do not get the support needed following a bereavement, often because they are not 'seen' by decision makers: the homeless, those involved in the criminal justice system, those people who have learning disabilities and those whose cultures involve nomadic lifestyles.

Cultural insensitivity and inequalities

End of life experiences and disrupted traditions

The Commission heard that there is insufficient cultural sensitivity training among white care providers. Participants gave examples of racial discrimination, cultural insensitivity and lack of dignity in end-of-life care provided to dying family members. Delays to prompt burial arrangements impacted on families and communities who could not appropriately express their respect and love for the person who had died, resulting in feelings of shame and guilt.

The pandemic also impacted on decisions to seek health care by underserved communities. The Commission heard that certain communities stopped sending sick relatives into hospital, fearing that they wouldn't see them again.

"... we had a mixture of people who said they're not going to send their loved one to the hospital, even though there were chances of they could have lived, because they were just too scared that once they go into that ambulance and those doors close, they will never see that loved person again..." – Oral evidence

"...Why do black people have to take so long with their funerals, 20 minutes is what you get, why do you need half a day?" – oral evidence

Immigration policies, and pending Bill, make it difficult for Black, Asian and ethnic minority families to fulfil wishes relating to repatriation of bodies and bringing overseas family members to the UK for funerals, preventing them from being able to grieve in the way that would like and expect. Therapists supporting people from minority backgrounds are witnessing links between racism, suicide and mental health problems.

The struggle for support

Minority groups such as ethnic and faith minorities are less likely to access formal support – both due to cultural norms and stigma around seeking support outside the family, and due to lack of appropriate support made available.

"A recent mapping of ethnic minority mental health services in the UK found that ethnic minority groups were less likely to use mainstream bereavement support services. Access issues and a lack of culturally sensitivity in the way services were designed so they did not meet the needs of specific communities were cited as barriers." –25 organisational respondent

"My husband is Black and there is a stigma around receiving support or speaking to someone about your grief. I begged him to see the GP or speak to employee assist but to this day he never has" - Woman in her 40s whose father in law died of cancer (England)

“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.” – Woman in her 30s whose father died of COVID-19

Language barriers can be an issue for some people, particularly older generations who may struggle with English.

“My mother has not accessed counselling. She found talking about her issues was more triggering. There was a language barrier as English as a second language but did not always feel comfortable talking via a translator” – Woman in her 30s whose sister died of COVID-19 (England)

Evidence highlighted that there can be stigma associated with grief and related help-seeking, in particular following suicide or abusive relationships. Stigmatised and disenfranchised grief can mean that people feel unable to grieve in the way that they want to and need additional support to be able to do so.

Gypsy and traveller communities living on sites find it difficult to get enough privacy to access remote counselling support. Waiting lists and delayed access to support is a particular, as these communities may have moved before support becomes available.

Socio-economic factors also intersect with these issues, with the Commission hearing that a fifth of people on lowest incomes felt unsupported after bereavement compared to 10 per cent of those who were in the highest income groups.

Bereavement experiences of people experiencing homelessness

Homelessness is associated with many types of loss and trauma. People experiencing homelessness may have experienced bereavement (in particular sudden, unexpected deaths), intersected with other trauma and health problems. This, coupled with potentially reduced social support networks can make people in this situation vulnerable to complex grief reactions or make coping with grief difficult. Limited access to technology or limited access to information from health care professionals can mean that people experiencing homelessness are not able to access satisfactory information regarding those close to them are dying or who have died. They are often not invited, or unable to attend, funerals and memorial services which compounds their grief, feelings of shame and excludes them from normal grieving process.

Bereavement experiences of those with learning disabilities

People with learning disabilities commonly experience bereavement and loss, particularly of friends in special needs schools or supported housing. Previously, a commonly held misperception that they won't understand and therefore do not grieve has been replaced with compassion, understanding and better knowledge in support those with learning disabilities in their bereavement. However, there are still cases where people are excluded from the usual grieving process, due to a misconception that they will not benefit from current bereavement services.

LGBTQ experiences and needs

A systematic review shared in the organisational evidence identified that LGBT+ people are at increased risk of certain life-limiting illnesses including cancers and have higher rates of drinking, smoking, drug use and mental health problems linked to discrimination. As such, many LGBT+ people will require palliative care and bereavement services. However, if these people and their partners have not shared their relationship through their family and friends, they are at risk of both disenfranchised and complicated grief.

Experiences and needs of people in prison

Bereavement can often be a trigger for decisions that lead people into the criminal justice system. Once in the system, the challenging prison environment can make it difficult for prisoners to express their grief and display vulnerability. People in prison often experience disenfranchised grief: they may be informed of a death at a different time to the family, they may not be able to attend the funeral, and are isolated from the normal support many of us have – their family and friends.

Recommendations

The Commission has several recommendations to improve bereavement support for these underserved communities, including

- a commitment for the government to ensure these communities are front and centre of funding initiatives.
- all organisations supporting bereaved people must commit to tackling inequalities in access to bereavement support, ensuring underserved communities are better supported
- Every UK government must commission specific research to better understand the support needs of bereaved people from ethnic minority communities, including those whose grief is disenfranchised.

To underpin these commitments, a 79p per person of funding is required to transform bereavement services over the coming 5 years, with a particular focus on better supporting Black, Asian and ethnic minority communities and other groups who are poorly served.

Appendix D: Demographics and Descriptive Data

Respondent Demographics

Respondents to the adult, young person and child surveys were asked a variety of questions to better understand what types of people the survey reached, and to better understand to whom the insights revealed in the survey can be generalized. As the survey is read, it is important to keep these demographics in mind to recognize who the report best represents.

A. Age

Adult survey responders were asked to which age group they belonged. The largest age groups represented were middle-aged adults in the 41-50 and the 51-60 age groups, with 53% of responders belonging to these groups. However, the survey reached a wide age range from as young as 18 to over 90 years old. The specific proportions can be seen in the table below, organized from youngest to oldest.

Age Groups of Adult Respondents

Age Group	Proportion of Respondents	Number of Respondents
18-30	6.33%	71
31-40	14.63%	164
41-50	26.32%	295
51-60	27.12%	304
61-70	15.97%	179
71-80	8.21%	92
81-90	1.25%	14
Over 90	0.18%	2

Note. N = 1,121

Young person and child responders were asked to share their exact ages, which spanned from seven to seventeen years old. There were 99 children and young people in total. For the younger cohort, who were all under the age of

12, most were clustered towards the other ages in the group. For the older cohort, 16- and 17-year-olds, most were 17. The exact breakdown of the age groups can be seen below.

Age Groups for Children and Young People

Age	Proportion of Respondents	Number of Respondents
7	2%	2
8	3%	3
9	2%	2
10	5%	5
11	4%	4
12	5%	5
13	18%	18
14	24%	24
15	11%	11
16	3%	3
17	10%	10
No Response	12%	12

Note. N = 99

B. Gender

Survey responders were asked to share their gender identity. A significant majority of the respondents identified as women. The specific proportions can be seen in the table below, organized from largest to smallest group reached.

Gender of Respondents

Gender	Proportion of Respondents	Number of Respondents
Cisgender Woman	86.24%	965
Cisgender Man	10.99%	123
Preferred not to say	1.07%	12
Non-Binary/Gender Fluid	0.45%	5
Transgender Man	0.18%	2
Transgender Woman	0.09%	1

Note. N = 1,108

Children and young people were also asked their gender. The younger cohorts had more female participants, and the oldest cohort was evenly divided between male and female participants. The overall gender demographics was 32% male, 58% female, with the remaining 10% not disclosing their gender.

C. Sexual Orientation

Survey Responders were asked to share their sexual orientation and 5.80% reported they identified as a member of the LGBTQ+ community. The specific proportions of responses can be seen in the table below, organized from largest to smallest group reached.

Sexual Orientation of Adult Respondents

Sexual Orientation	Proportion of Respondents	Number of Respondents
Heterosexual	86.25%	960
Prefer not to say	5.55%	62
Bisexual	2.79%	31
Gay/Lesbian	2.15%	24
*Other	1.16%	13

Note. N = 1, 090

* Note: All 13 of the participants who selected "other" provided further details. The largest group was "Asexual" (53.85%, n = 7). The rest were heterogeneous.

D. Ethnicity and Nationality

Adult survey responders were asked to share their ethnicity and/or UK nationality. Due to an unfortunate technical glitch, there was no ethnicity or nationality data for 20% of participants. For those from whom ethnicity and/or UK nationality data was collected, most (84%) indicated they were White (20%), English (45%), or White and English (19%) and 10% reported being from a minority ethnic background. Full details can be seen in the table below in with categories listed from most to least frequently reported.

Ethnicity and UK Nationality of Adult Respondents

Ethnicity	Proportion of Respondents	Number of Respondents
UK- England	51.10%	572
White	32.25%	372
UK- Scotland	4.80%	54
UK- Wales	3.80%	43
Asian/Asian British	2.00%	22
Black (African Caribbean or British)	1.80%	20
Any Other Background	1.80%	20
Republic of Ireland	1.60%	18
UK- Northern Ireland	0.90%	10
Pakistani	0.90%	10
Other Mixed Background	0.80%	9
Indian	0.60%	7
Other Black	0.40%	4
Jewish	0.40%	5
Arab	0.20%	2
Mixed Background	0.20%	2
Gypsy or Irish Traveler	0.10%	1
Data Missing	20%	226

Note. N = 893

Note: Participants were asked to check all that applied, so the sum total will not equal 100%.

Children and young people were also asked about their ethnicity and/or UK nationality. 71% said they were White, either from the UK or elsewhere, 23% had missing or unclear data about their ethnicity, and 4% said they were from a background.

E. First Language

Adult participants were asked to indicate what was their first language. English was the first language for 96% of the participants. For those with a different first language, a quarter spoke Welsh and the remaining were heterogenous, with most being European.

Children and young people were also asked about their first language. In the 5-12 and 17-18 age groups, almost all (95%) said English was their first language, with one participant indicating they spoke two languages at home (what those languages were was not specified) and one other choosing not to answer the question. There was greater diversity in the 13-15 age group, in which 47% spoke English alone at home, a further 6% said they spoke English and another language at home, 13% reported speaking another language at home and the final 13% had missing data for this question.

F. Education

Adult participants were asked to share their highest level of educational attainment. Most participants (85.60%) had gone further than compulsory education and a large portion (63.30%) had a university degree. Exact responses are listed below, grouped from least to most advanced.

Educational Level of Adult Respondents

Education Level	Proportion of Respondents	Number of Respondents
No Qualifications	2.69%	30
GCSEs/O Levels/CSEs	11.74%	131
A Levels/GNVQs/BETC	13.08%	146
Trade Apprenticeship	0.99%	11
ONC/OND/City & Guilds	4.57%	51
HNC/HND	3.85%	43
University First Degree	28.67%	320
Postgraduate Diploma	11.02%	123
Postgraduate Degree	19.98%	223
*Other	2.79%	31

Note. N = 1,109

**Note: For the "other" category, the most common qualifications reported were nursing related (30.00%, n = 9). The remaining 70.97% of "other" qualifications were largely heterogeneous.*

G. Employment

Adult survey responders were asked to share their current employment status, including if they were unemployed, a student, or retired. Most respondents (62%) were employed either part of full time, with just under half of the remaining participants being retired. Full details are listed in the table below, reported from most to least frequently reported employment status.

Employment Status of Adult Respondents

Employment Status	Proportion of Respondents	Number of Respondents
Full-Time Work	41.47%	464
Part-Time Work	20.64%	231
Retired	17.16%	192
Other	4.92%	55
Permanently Unable to Work	4.02%	45
Carer	3.84%	43
Looking After Home	3.93%	44

Unemployed	2.41%	27
Full-time Education	1.34%	15

Note. N = 1,116

*For the "other" category, the most commonly qualifications mentioned were volunteer work 21.81% (n = 12), self-employment 21.81% (n = 12), and temporary unemployment due to illness, maternity, or bereavement 12.73% (n = 7). The remaining 40.00% (n = 22) of "other" forms of employment or unemployment were largely heterogeneous.

Young people were asked if they were in education, employment, or other circumstances. Most (67%) were in full time education, and there was one person each (7%) who indicated that they were a carer, unable to work due to sickness or disability or "something else" (specifics not provided). Two did not answer the question (13%).

H. Region

Adult participants were asked to share in which region of the UK they lived from a drop-down menu. Results are listed below, with regions listed alphabetically.

Region of the UK- Adults

Region	Proportion of Participants	Number of Participants
Channel Islands	0.09%	1
Living Overseas	0.36%	4
East Midlands	5.99%	67
East of England	5.64%	63
Greater London	10.91%	122
Isle of Man	0.09%	1
Northeast England	4.20%	47
Northwest England	12.52%	140
Northern Ireland	1.70%	19
Scotland	5.55%	62
Southeast England	18.87%	211
Southwest England	10.82%	121
Wales	9.84%	110
West Midlands	7.78%	87
Yorkshire & the Humber	5.28%	59
No Response	0.36%	4

Note. N = 1,118

Children and young people were also asked which region of the UK they currently lived in. The largest groups were in Southeast England and Wales, but many parts of the UK were represented. Full responses are listed below, listed alphabetically.

Region of the UK- Children and Young People

Region	Proportion of Participants	Number of Participants
Channel Islands	1%	1
Living Overseas	3%	3
East Midlands	20%	18
East of England	10%	9
Greater London	1%	1

Isle of Man	2%	2
Northeast England	1%	1
Northwest England	-	-
Northern Ireland	2%	2
Scotland	2%	2
Southeast England	12%	11
Southwest England	7%	6
Wales	10%	9
West Midlands	13%	12
Yorkshire & the Humber	2%	2
No Response	14%	13

Note. N = 99

I. Religion

Adult participants were asked to share their religion from a drop-down menu. Results are listed below, with religions listed alphabetically.

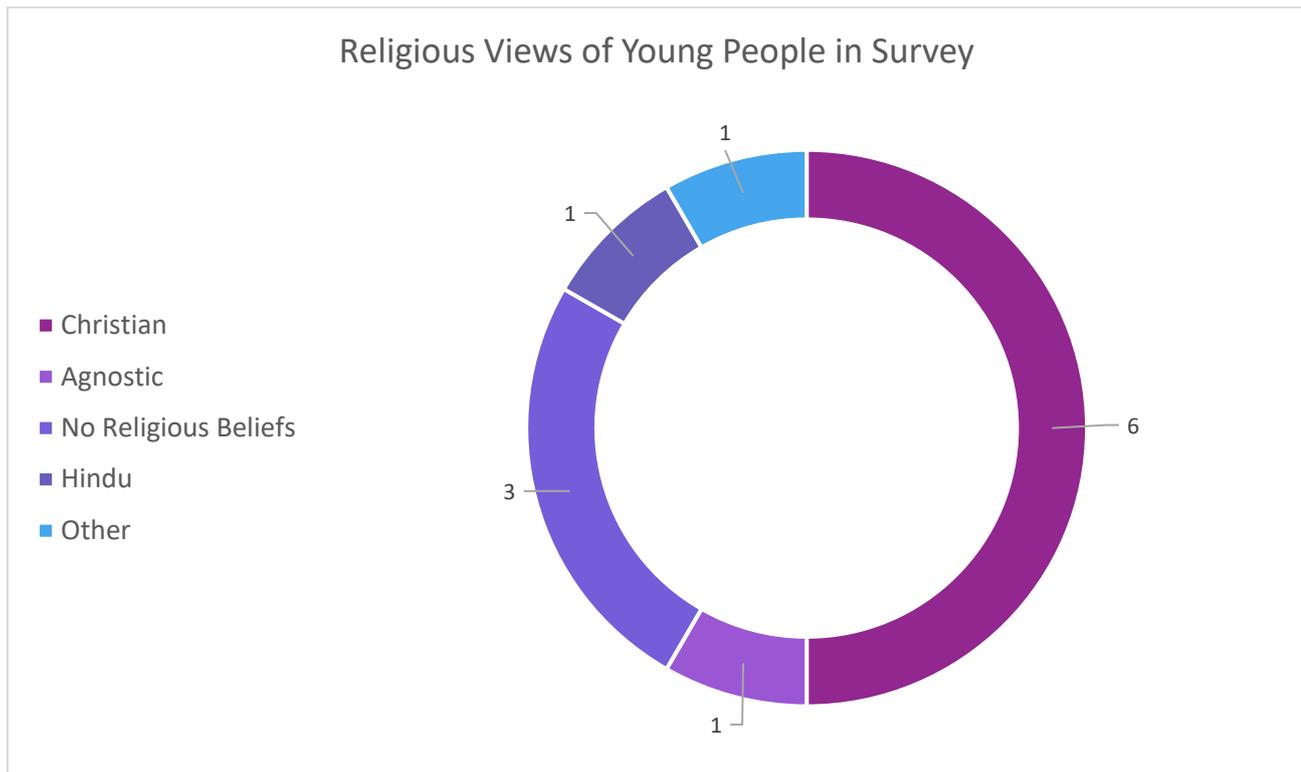
Religious Beliefs of Adult Participants

Religious Belief	Proportion of Respondents	Number of Respondents
Agnostic	7.12%	79
Buddhism	0.72%	8
Christianity all denominations	40.63%	451
Do not wish to say	5.68%	63
Hinduism	0.18%	2
Islam	1.53%	17
Judaism	0.72%	8
No religious or spiritual beliefs	24.32%	270
*Other	2.16%	24
Sikhism	0.36%	4
Spiritual but not religious	11.62%	129
No Response	4.95%	55

Note. N = 1,110

*All 24 participants who selected "other" provided further details. The largest group was "Humanist" (16.67%, n = 4) followed by "Atheist," (12.50%, n = 3) with the remaining (70.835, n = 17) being heterogenous.

Young people were also asked about their religious beliefs. Their responses are shown in the pie chart below.



Note. N = 13

J. Disability

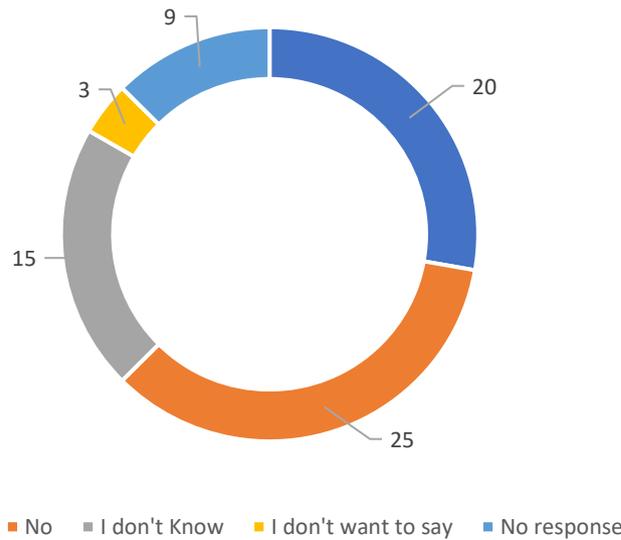
Children and young people were asked if they had a disability. Thirteen of them indicated that they did, and six of those provided details as follows:

- ADHD: $n = 2$
- Deaf: $n = 1$
- APD and PTSD: $n = 1$
- Autism: $n = 2$

K. Caring Status

Children and young people were also asked if they had been a carer for the person who died. Twenty of them said they were, though there may have been a lack of understanding about the question, as fifteen children said that they didn't know, and nine more left the question blank. A further twenty five said no and three said they did not want to say.

Children and Young People's Caring Status



Note. N = 72 children and young people.

Characteristics of Bereavements

Participants were asked to share details of how they had been bereaved in the last five years. Respondents shared how many bereavements they had in the last five years, and their relationships with those people. They then chose one specific bereavement to complete the rest of the survey. This section contains general information shared about the bereavements to provide context for the grief the participants speak about in more detail further in the report.

A. Bereavements in last five years

i. Total Amount

Participants were asked to share which people they had been bereaved of in the last five years and most reported having one or two bereavements. All responses were tallied, and their total number of bereavements over the last five years are listed below.

Total Bereavements- Adults

Bereavements in last Five Years	Proportion of Respondents	Number of Respondents
One	64.70%	735
Two	21.70%	243
Three	8.30%%	93
Four	2.70%%	30
Five	1.30%	14
Six	0.30%%	3
Seven	0.10%	1

Note. N = 1,119 adults.

ii. Total Types of Bereavement

Adult participants were also asked to share their relationship to the people they have been bereaved of in the past five years. Husbands/male partners and parents were the most commonly reported types of bereavements.

Relationships of Bereavements from Last Five Years- Adults

Relationship	Proportion of Respondents	Number of Respondents
Husband/Male Partner	34.40%	385
Wife/Female Partner	6.20%	69
Father	24.10%	270
Mother	25.90%	290
Brother	4.10%	46
Sister	3.80%	42
Son	5.10%	57
Daughter	4.90%	55
Grandparent	7.90%	88
Grandchild	0.18%	2
Aunt or Uncle	9.40%	105
Friend	11.30%	127
Colleague	2.60%	29
Other	10.80%	121

Note. N = 1,119

Note: Participants were asked to check all that apply, so the totals will be larger than 100%.

Children and young adults were also asked of whom they had been bereaved. Most had lost a parent or grandparent. Full results can be seen in the table below. Please note that children could list more than one loss.

Relationships of Bereavements from Last Five Years- Children and Young People

Relationship	Proportion of Respondents	Number of Respondents
Father	29%	27
Mother	13%	12
Brother	3%	3
Sister	3%	3
Aunt or Uncle	10%	9
Grandparent	33%	30
Someone else in the family	15%	14
Friend	3%	3
Other	11%	10
Girlfriend/Wife/Female Partner (From 16-17 age group)	1%	1

Note. N = 99 children and young people.

B. Specific Bereavement for Survey

i. Type of Bereavement

Adult participants were asked to choose one specific bereavement from the last five years on which to focus their responses to the survey. Results are listed below, from the most to least frequently reported bereavement of focus.

Specific Bereavement: Relationship

Relationship	Proportion of Respondents	Number of Respondents
Husband/male partner	33.01%	370
Mother	19.36%	217
Father	16.41%	184
Wife/female partner	5.89%	66

Son	5.00%	56
Daughter	4.46%	50
*Other	4.20%	17
Friend	3.30%	37
Sister	2.50%	28
Grandparent	2.41%	27
Brother	2.23%	25
Aunt or Uncle	1.52%	17
Father-in-Law	0.63%	7
Cousin	0.54%	6
Mother-in-Law	0.45%	5
Niece	0.45%	5
Sister-in-Law	0.36%	4
Colleague	0.09%	1

Note. N = 1,119

* Specific bereavements originally listed in "other" with three or more cases were given their own named category. The cases remaining in 'other' are heterogenous.

ii. Age of Deceased

Adult participants were asked to which age group the person who died belonged. Roughly half were over 65 years old, but the full spectrum of ages were represented. Results are listed below, from youngest to oldest.

Age at Death- Adult Bereavements

Age Group	Proportion	Number
Under 18	6.16%	69
19-24	1.25%	14
25-29	1.88%	21
30-34	2.68%	30
35-39	5.64%	52
40-44	4.38%	49
45-49	6.61%	74
50-54	7.50%	84
55-59	7.59%	85
60-64	7.14%	80
65-69	7.86%	88
70-74	10.00%	112
75-79	9.29%	104
80-84	8.93%	100
85-90	6.96%	78
Over 90	6.88%	77
*No response	0.36%	4

Note. N = 1,119

*The four no responses for age were for someone's mother, father, wife and husband, so are all presumably of adult age.

Young people aged 16-17 were also asked to which age group the person who died belonged. Results are listed below, from youngest to oldest.

Age at Death- Young Adult Bereavements

Age Group	Proportion	Number
Under 18	8.33%	1
25-29	8.33%	1
35-39	16.67%	2

40-44	25.00%	3
45-49	8.33%	1
50-54	16.67%	2
65-69	16.67%	2

Note. $N = 12$

iii. Gender of Deceased

Adult participants were asked to which gender the person who died belonged. They shared that most were male (Male: 61.20%, $n = 686$), with a significant minority being female (38.54%, $n = 432$). There were three cases of bereavement due to miscarriage in which the child's gender was not listed as male or female, and instead there was no response to the question (0.18%, $n = 2$) or a response of non-binary (0.09%, $n = 1$).

iv. Place of Death

Adult participants were asked where the person they were bereaved of had died. Most died either in a hospital or at their home. The full list of responses are listed below, from most to least frequent.

Location of Death

Location	Proportion	Number
In hospital	46.88%	525
In their home	29.55%	331
Died somewhere else (such as at scene of an accident)	7.86%	88
In a hospice	7.50%	84
In a care home	7.23%	81
I don't know	0.54%	6
No response	0.45%	5

Note. $N = 1,119$

v. Cause of Death

Adults and young people aged 16-17 were asked of what the person they were bereaved of had died. For adults, about half died either due to cancer or to confirmed or suspected COVID-19 infection, full details can be seen in the table 'Causes of Death.' The 'other' category represented about 40% of deaths, and details of these are provided in a separate table, 'Other Causes of Death.'

Young people had a much more heterogenous range of causes of deaths, with 62% being due to "other" causes. The remaining causes were terminal/life limiting condition (8%), COVID-19 (8%) and cancer (15%).

Causes of Death

Condition	Proportion	Number
Cancer	28.00%	313
Confirmed or suspected COVID-19 th	19.95%	223
Other terminal/life limiting condition	9.93%	111
*Other	41.23%	461

Note. $N = 1,108$

*Other categories are shown below.

Other Causes of Death

Death in "Other" Category	Proportion	Number
Cardiac-Related	7.20%	80
Multiple factors	4.14%	46
Miscarriage, stillbirth, neonatal death and SIDS	3.60%	40
Suicide	3.06%	34
Accident	2.97%	33
Stroke	1.98%	22
Dementia	1.17%	13
Unknown	1.17%	13
Sepsis	1.17%	13
Alcohol Dependency	0.99%	11
Miscellaneous representing less than 1% each of total	14.04%	156

Note. N = 461

Note. Percentages under "other" are given are for overall deaths, not proportion of "other" deaths.

Appendix E: Quantitative Tests of Demographic Group Differences

Notes

- If a result is described as "not significant" it means that people in the various categories of the demographic variable (i.e., age, gender, nation of residence) did not answer the question differently from one another.

- Likewise, if a result is described as “significant” it means that people in the various categories of the demographic variable answered the question differently. In these instances, additional details will be provided to explain the nature of the difference.
- For some tests, some group categories had to be collapsed together or removed due to logistical constraints. When this has been done it will be clearly indicated.

Age

Age was coded into the groups below when possible, but often the older age groups were condensed due to low case numbers.

- 18-30 years old
- 31-40 years old
- 41-50 years old
- 51-60 years old
- 61-70 years old
- 71-80 years old
- 81-90 years old
- Over 90 years old

Employer Support Level

The 81-90 and 90+ age groups were excluded due to insufficient cases

Chi-Square results were significant with a small effect size, $\chi^2(12) = 22.15$, $p = .036$, $\phi_c = .10$. Examination of the crosstabs showed that those in 31-40 were less likely to say they had been “not at all supported” and more likely to say they were “fairly well supported.”

Education Setting Support Level

Data was not appropriate for either an ANOVA or a Chi-Square Analysis due to cell sizes not having enough cases, even with the smallest age groups dropped.

Formal Support

- Need
 - The 81-90 and 90+ age groups were excluded due to insufficient cases.
 - Chi-Square results were significant with a small to medium effect size, $\chi^2(10) = 77.32$, $p < .001$, $\phi_c = .19$. Examination of the crosstabs showed that participants in age groups younger than 50 were more likely to want support services, with the preference being the strongest for people in the 31-40 and 41-50 age groups. Those in the 61-70 and 71-80 age groups were the least likely to want support services. Those in the 61-70 age group were more likely to be unsure about if they needed services than the other age groups.
- Access
 - The 81-90 and 90+ age groups were excluded due to insufficient cases.
 - Chi-Square results were significant with a small to medium effect size, $\chi^2(5) = 52.13$, $p < .001$, $\phi_c = .22$. Examination of the crosstabs showed that those under age 50 were more likely to have access services than those over 50.

Informal Support Sources

One-way ANOVA results were significant with a small to medium effect size, $F(5, 1097) = 6.34$, $p < .001$, $\eta^2 = .03$. Post hoc tests (Tukey’s HSD) revealed that those in the 31-40 age group received significantly more informal support ($M = 2.02$, $SD = 1.15$) than those in the 41-50 age group ($M = 1.66$, $SD = 1.19$), the 51-60 age

group ($M = 1.61, SD = 1.18$), the 61-70 age group, ($M = 1.41, SD = 1.07$), or the 71-80 age group ($M = 1.38, SD = 0.91$). It was marginally higher ($p = .051$) than those in the 18-30 age group ($M = 1.56, SD = 0.94$).

Number of Practical Difficulties

Data was not appropriate for either an ANOVA or a Chi-Square Analysis due to cell sizes not having enough cases, even with the smallest age groups dropped.

Number of COVID-19 disruptions

Data was not appropriate for either an ANOVA or a Chi-Square Analysis due to cell sizes not having enough cases, even with the smallest age groups dropped.

Number of obstacles in accessing support

Chi-Square results were significant with a small effect size, $\chi^2(8) = 27.17, p < .001, \phi_c = .18$. Examination of the crosstabs showed that:

- those in the 18-30 age group and the 31-40 were both less likely to have just one obstacle and more likely to have two obstacles. Further, those in the 31-40 age group were also more likely to have three obstacles.
- Those who were in the 51-60 age group were more likely to have just one obstacle.
- Those who were between 41-50 and those over 60 were equally likely to have one, two, or three obstacles.

Gender

Gender was coded into three groups:

- Male
- Female
- Non-binary

Employer Support Level

One-Way ANOVA results were not significant; $F(1, 681) = 0.63, p = .429, \rho\eta^2 = .00$

Education Setting Support Level

One-Way ANOVA results were not significant; $F(1, 133) = 3.11, p = .080, \rho\eta^2 = .02$

Formal Support

- Need
 - Chi-Square results were significant, with a small effect size, $\chi^2(2) = 25.35, p < .001, \phi_c = .15$. Examination of the crosstabs showed that women were more likely to want services.
- Access
 - Chi-Square results were significant with a small effect size, $\chi^2(1) = 5.48, p = .02, \phi_c = .07$. Examination of the crosstabs showed that women were more likely to access services.

Informal Support Sources

One-Way ANOVA results were not significant; $F(1, 1086) = 0.03, p = .858$

Number of Practical Difficulties

Groups with 3 and 4 reported difficulties were collapsed into one "3+" category. Chi-Square results were not significant; $\chi^2(2) = 2.42, p = .298$

Number of COVID-19 disruptions

Groups with 8 and 9 reported disruptions were collapsed into one "8+" category. Chi-Square results were not significant; $\chi^2(7) = 9.89, p = .195$

Number of obstacles in accessing support

Chi-Square results were not significant; $\chi^2(2) = 0.30, p = .859$

Education

Education level was coded into three levels:

- **Compulsory education**, for those with no qualifications or GCSEs/O Levels/CSEs
- **Further education** for those with A Levels/GNVQs/BETC, Trade Apprenticeships or ONC/OND/City & Guilds.
- **Higher education** for those with HNC/HND University First Degree, Postgraduate Degrees or Postgraduate Diplomas.

Employer Support Level

One-Way ANOVA results were not significant; $F(2, 685) = 1.39, p = .25, \rho\eta^2 = .00$

Education Setting Support Level

One-Way ANOVA results were not significant; $F(2, 130) = 1.76, p = .18, \rho\eta^2 = .03$

Formal Support

- Need
 - Results were significant; $\chi^2(4) = 21.11, p < .001$, Cramer's $V = .10$, such that those who had attended higher education (3) were less likely to say they needed formal support. Those who were in further education (2) were more likely to say they needed support. Differences were not significant for those who had completed only compulsory support.
- Access
 - Chi-Square results were not significant; $\chi^2(2) = 5.04, p = .080$

Informal Support Sources

One-Way ANOVA results were significant, $F(2, 1074) = 9.22, p < .001, \rho\eta^2 = .02$, indicating education level had a significant impact on the number of sources of informal support people received. Tukey's Post-hoc tests showed that those who completed higher education had ($p < .05$) more sources of informal support ($M = 1.73, SD = 1.19$) than those who had completed only compulsory education ($M = 1.35, SD = 1.00$) or further education ($M = 1.50, SD = 1.05$). There were no differences between those who completed compulsory or further education.

Number of Practical Difficulties

Groups with 3 and 4 reported difficulties were collapsed into one "3+" category.
Chi-Square results were not significant; $\chi^2(4) = 6.31, p = .177$

Number of COVID-19 disruptions

Groups with 8 and 9 reported disruptions were collapsed into one "8+" category.
Chi-Square results were not significant; $\chi^2(14) = 15.13, p = .369$

Number of obstacles in accessing support

Chi-Square results were not significant; $\chi^2(4) = 0.73, p = .948$

Four Nations

The four nations considered were:

- England
- Wales
- Scotland
- Northern Ireland

Employer Support Level

One-Way ANOVA results were not significant; $F(3, 689) = 0.32, p = .812$

Education Setting Support Level

One-Way ANOVA results were not significant; $F(3, 131) = 0.96, p = .413$

Formal Support

- Need
 - Chi-Square results were not significant; $\chi^2(6) = 11.77, p = .067$
- Access
 - Chi-Square results were not significant; $\chi^2(3) = 6.59, p = .086$

Informal Support Sources

One-Way ANOVA results were not significant; $F(3, 1102) = 0.92, p = .430$

Number of Practical Difficulties

Chi-Square results were not significant; $\chi^2(6) = 11.25, p = .507$

Number of COVID-19 disruptions

Chi-Square results were not significant; $\chi^2(27) = 29.69, p = .328$

Number of obstacles in accessing support

Chi-Square results were not significant; $\chi^2(6) = 5.93, p = .431$

LGBTQ+ Status

People were coded as having a LGBTQ+ identity if they reported a sexuality other than heterosexual or if their gender identity was neither cisgender male nor cisgender female.

Employer Support Level

One-Way ANOVA results were not significant, $F(1, 642) = 0.17, p = .682$.

Education Setting Support Level

One-Way ANOVA results were not significant, $F(1, 124) = 0.22, p = .639$.

Formal Support

- Need
 - Chi-Square results were not significant, $\chi^2(2) = 0.80, p = .671, \varphi_c = .03$
- Access
 - Chi-Square results were not significant, $\chi^2(1) = 0.85, p = .356, \varphi_c = .03$

Informal Support Sources

One-Way ANOVA results were not significant; $F(3, 1023) = 0.26, p = .614$

Number of Practical Difficulties

Groups with 3 and 4 reported difficulties were collapsed into one "3+" category.

Chi-Square results were not significant; $\chi^2(2) = 1.08, p = .581$

Number of COVID-19 disruptions

Groups with 6, 7, 8 and 9 reported disruptions were collapsed into one "6+" category.

Chi-Square results were not significant; $\chi^2(5) = 4.03, p = .545$

Number of obstacles in accessing support

Data was not sufficient for analysis due to cell sizes not having enough cases.

Support Obstacle of not feeling support would help them

- A Chi-Square test of independence was run to test if having a LGBTQ identity meant that someone was more likely to not access desired support because they did not think it would help them.
 - A significant relationship with a small effect size was found, $\chi^2(1) = 6.96, p = .008, \varphi_c = .13$, such that those who had a LGBTQ identity more likely to believe that support wouldn't provide the help they needed.

Minority Ethnicity Status

People who reported an ethnic identity that was black, Asian, Gypsy or Irish Traveller, or Arab; or a mixed identity that included at least one of these groups, were considered to come from a minority ethnic background.

Employer Support Level

One-Way ANOVA results were not significant, $F(1, 695) = 1.01, p = .316$.

Education Setting Support Level

One-Way ANOVA results were not significant, $F(1, 134) = 0.22, p = .646$.

Formal Support

- Need
 - Chi-Square results were not significant, $\chi^2(2) = 1.86, p = .395, \phi_c = .04$, such that there were similar rates for desiring support services regardless of participants' ethnicity.
- Access
 - Chi-Square results were not significant, $\chi^2(1) = 0.20, p = .653, \phi_c = .01$, such that there were similar rates for accessing support services regardless of participants' ethnicity.

Informal Support Sources

One Way ANOVA. No significant difference, $F(3, 1117) = 0.01, p = .936$

Number of Practical Difficulties

Groups with 3 and 4 reported difficulties were collapsed into one "3+" category.
Chi-Square results were not significant, $\chi^2(2) = 2.90, p = .234$

Number of COVID-19 disruptions

Groups with 8 and 9 reported disruptions were collapsed into one "8+" category.
Chi-Square results were not significant, $\chi^2(7) = 2.56, p = .923$

Number of obstacles in accessing support

Chi-Square results were not significant; $\chi^2(2) = 0.73, p = .695$

Appendix F: Votes for Schools report on Grief Education

In addition to the children and young people's call for evidence, the UK Commission also worked with Votes for Schools to find out what children and young people thought about loss and bereavement, specifically if this subject should be taught at educational settings. Over 31,000 children and young people took part in the vote, considering the following topics:

Primary topics

'Is loss too hard to talk about?'

'Should all children learn about coping with loss and bereavement at school?'

Secondary and College topic

'Should learning about coping with loss and bereavement be included on the curriculum?'

The results were fascinating: nuanced and thoughtful. The comments from all school years highlighted that there are clear concerns and fears children and young people had about such an important topic.

Overall, primary school pupils acknowledged that loss and bereavement was hard to talk about (59.5% voted yes) but 58.1% of pupils voted to have lessons about how to cope with loss and bereavement on the curriculum. College students agreed with their younger cohorts, with 65.2% of students voting 'yes' for inclusion of loss and bereavement as a learning topic.

However, most secondary school students believed that loss and bereavement was something that should not be taught, with 61.6% of pupils voting 'no'. This indicates a potential shift in attitudes around education of loss and bereavement. Further research into this area would clarify if this is down to societal attitudes influencing student perception, or if it is more likely that personal experiences of grief and bereavement occur by the time students reached secondary school.

The importance of grief education

The students who voted 'yes' felt that this topic was important and needed to be taught, due to the understanding that **loss and bereavement is a universal experience** that everyone will be affected by at some point in their lives. Outside the Votes for School responses, other children, young people, parents and organisations working with bereaved children agreed that **grief education was essential**. Grief education would help all children and young people to understand what happens when you are bereaved, to support others going through a bereavement and to support themselves if it happens to them. Grief education would be helpful to challenge unhelpful narratives, expectations and language around bereavement, both from peers and from staff.

"Yes because eventually everyone is going to go through this so if they know how to cope or help people then it will be much easier." – Primary school response

"We think yes because everyone is going to experience loss at some point" – Primary school response

This change should start in school where death is often already within the curriculum by accident but never discussed, one only has to look at primary schools all of whom teach fairy tales, most of which feature a dead parent, but this element is never opened for informed discussion.

(Oral evidence session)

Students also noted that by learning about loss and bereavement, they would be more **prepared for the future**, by understanding that the **experiences and feelings you may have are normal**. Students were especially aware that learning about this topic would support them, with many pointing out that strategies about coping would be welcome.

"We should talk about it as it is a reality in life and a skill we need to learn for life". – Primary school response

"I believe that is a big life skill to learn how to deal with grief, and losing a loved one can change someone's life forever." – Secondary school response

"As a Thrive school, many children felt it was healthy to talk about loss and bereavement and link our emotions and strategies to cope." – Primary school response

"I think I will deal with bereavement when I have to but it would be good to have a range of strategies to choose from." – Secondary school response

Others highlighted the importance of **understanding and supporting those peers and friends** who may be experiencing a bereavement during school life.

"It was really good this topic because if you know how someone feels, you can help them." – Primary school response

"I think it was a great topic because it really touched people's hearts and I think we can learn more about it since lots of people go through it and we can learn how to behave around people who are grieving." – Secondary school response

"Made us think of ways we can help each other, it can help maintain good friendships understanding each other." – Secondary school response

Some pupils made the connection that there will be **bereaved peers** who are dealing with this situation, and an awareness that it would **support pupil's mental health overall**.

"I think it is a great idea because me being someone that lost someone close to me I find it quite hard to cope with my emotions and I keep it quite bubbled up and I don't tell anyone about how I'm feeling." – Primary school response

"I would say about 1 of 5 people in this school have had to deal with loss at some point in their lives, so whether they dealt with it alone or had someone to help them, it would help even just the slightest bit to have some support, other than the pastoral." – Secondary school response

"Everyone deals with loss so it is important that we know how to healthily cope with it without jeopardising our mental health in the long term." – Secondary school response

"However, our feelings are valuable and important, and recognising them is worthwhile." – Secondary school response

One comment highlighted that loss and bereavement applies to **other forms of change (loss)** and this understanding could help to support students:

"It was an eye-opener to realise that some children may be angry about moving school, we should have a better understanding. "

(Primary school response)

Curriculum: sensitivity and choice

However, this education needs to be **planned sensitively**, to ensure it is relevant for all age/developmental groups, including how to manage bereaved pupils appropriately. Students and teachers offered **ideas and suggestions** about

how to include bereavement on the curriculum appropriately and sensitively, which was echoed by childhood bereavement organisations in the call for evidence.

While there was agreement about teaching about loss and bereavement in educational settings, there was a range of responses about when to teach this topic:

"If it is going to be taught, it should be taught when children are young, because losing someone can happen at any point in a child's life - not just high school or college." – College response

"Maybe implementing it from nursery will be better so children take the topic seriously." – College response

"It's not always easy for youngsters to think about this topic - perhaps not too in depth if it is taught in schools?" – Secondary school response

"Maybe teach in older years only." – Secondary school response

Year 9 said that it would be really helpful if the students were given the option over whether they wanted to talk about it or not.

Y9- The topic should be available on curriculum but not a forced topic. As it is a sensitive topic and it is different for everyone, one size does not fit all.

Y11- IT should not be a one off topic but not overly visited. Once per term and make use if professional resources, for example counsellors

It depends what subject. Maybe it should be discussed in Biology, RE or health and social care.

(All Secondary school responses)

Having a **whole school approach to bereavement** will help to place **grief education within a framework of compassion and support**. Bereaved children, young people, parents and organisations highlighted the importance of bereavement training for schools and educational settings – helping the staff team to be bereavement-aware, being confident in acknowledging a death has happened, and to have important conversations with the bereaved pupil and their family/caregivers about what the school offers (which would be highlighted in the bereavement policy). Bereavement leads within each setting, acting as a single point of contact for bereaved pupils and their families/caregivers, would also help to ensure that the school or setting is able to appropriately support both staff and pupils around grief education.

"We can embrace] the subject within PHSE to enable children to develop emotional literacy and coping skills for later life: developing other areas of the curriculum to include a focus on loss, death and grief, or as an opportunity to sensitively introduce the topics to pupils using age-appropriate language; encouraging engagement in honest conversations about death and promoting healthy discussions about grief to help prepare young people for bereavements." – Child bereavement service

Part of grief education could be the **development of mental health peer supporters or champions**, who can also offer peer support for bereaved peers. There was also a strong concern for teachers and other educators or allied professionals to be supported in having these important conversations through training.

And while there are schools which do include loss and bereavement on the curriculum, there were worries that teaching this subject could result in further academic pressure or would be a waste of time:

“Not enough specialism. Where would it be taught. Would there be an exam?” – Secondary school response

“What new things could possibly be taught to us? ‘Talk to an adult?’” – Secondary school response

There was also the recognition from all students that **trusted adults at school** and home were needed, regardless of whether the subject would be included in the curriculum, as well as the understanding that some students may benefit from **support outside and in spite of/instead of lessons** and a strong preference that **students should get to choose to attend lessons**, particularly if they have been bereaved or their personal circumstances are sensitive at time of teaching:

“Yes because if you are upset about something you can tell or a adult because we don’t want people upset with something. So talk to someone about it. Don’t keep quiet.” – Primary school response

“I can always talk to my teachers and other adults in the school, sometimes it just takes me time. They always make me feel better.” – Primary school response

“However, if you don't tell school about it, you should tell somebody else such as a friend, parent or other family member.” – Secondary school response

“if a student doesn’t feel safe or comfortable talking to someone at home, school (or someone at school) should be more safe for them to talk to. eg, a teacher, mentor”. – Secondary school response

“Schools should have a dedicated place for this rather than lessons”. – Secondary school response

Acknowledging bereavement and grief can be a sensitive topic to learn about

Regardless of their votes, it was clear that both students and teachers acknowledge that this was a sensitive topic, and that it was a subject that could **trigger strong feelings for themselves and their peers**.

“I think children shouldn’t talk about bereavement and loss at school because it could make children very upset and bereavement and loss is a upsetting topic to talk about it could be hard to cope with if your talking about it at school.” (Primary school response)

An additional worry that emerged, regardless of the vote, was the **expectation that pupils’ personal experiences would be shared**. This was something that many felt was inappropriate within a lesson on loss and bereavement:

“Forcing someone to talk about their emotions in a school setting isn't something that would help.” – Secondary school response

“Loosing someone is very personal and people may not feel comfortable talking about it in a lesson at school” – Secondary school response

Y8- “It would be a struggle to admit and expose a person's grief in class.” – Secondary school response

As noted above, students felt that loss and bereavement is a difficult topic to talk about. Due to this approach, they were then **worried about the reactions of their friends and peers**. This thoughtfulness and protectiveness of themselves and others is to be acknowledged.

“We shouldn't learn about it because it can be too personal and cause more sad feelings. If we share our losses with others, it can make them feel sad too.” – Primary school response

“Bringing these topics into a mandatory curriculum will be difficult for many students especially in a time when loss has been experienced by many in this unprecedented time. 2– Secondary school response

“Some do not agree because they think students will not want to talk about their loss and will just laugh it off and not take it seriously” - College response

A sub-theme that emerged highlighted that **school may be a safe space** for pupils who may be dealing with bereavements or other issues at home.

“No because some children may have had a loss recently and they may not like it if their school talks about losses because it will come up in their head again”. – Primary school response

“Some people find it hard to cope with loss and bereavement at home so need that support in schools.” – Secondary school response

Comments from students indicated that due to the very personal nature of bereavement and loss, it was best for children and young people to be supported by **their family and friends**, rather than learn about loss and bereavement in school. Additionally, there were comments noting that bereaved children need protection from further opportunities to feel their grief:

“I think it would be better to talk about loss and bereavement at home so they can talk to their own trusted adult.” – Primary school response

“Majority of class are more comfortable discussing these issues at home.” – Secondary school response

Some felt that loss and bereavement couldn't be taught at all – it is a **life lesson or experience** that cannot be prepared for:

*“I'm not sure it's something that *can* be taught until you experience it.” – Secondary school response*

“The boys in our form were certain that it shouldn't be included in the curriculum, they all said it's just something you have to deal with, that it's part of life. Most said it was something they would just deal with themselves and keep in.” – Secondary school response

“Wait and see until it happens and learn how to cope then”. – Secondary school response

Many students felt that grief was a very **individual experience** and that teaching about loss and bereavement (**not one size fits all**) would therefore exclude experiences or offer unfair or unrealistic expectations about 'how' to grieve:

“Everyone person is impacted differently with bereavement so it isn't possible to create lessons that everyone can follow” – Secondary school response

There was concern from both pupils and teachers about the right age to be taught about loss and bereavement (**age related comments, difficult to comprehend**). There was also concern that younger children might have feelings of **anxiety about loved ones** and the future when confronted by the topic of loss and bereavement. Some students and teachers felt that loss and bereavement should not be considered as a part of the curriculum:

“We feel it is covered within the mental health topics.”

“Bereavement doesn't have to be solved within the curriculum as there are many outside sources such as therapy and childline that can give support”.

(All Secondary school responses)

Other concerns about including grief education in settings

Others noted that **schools have limited resources**, and this particular topic could take time away from other forms of educational support. Finally, some students felt that being taught about loss and bereavement would be exposing or alienating in some way, with a concern that they would not **feel safe with their peers** if this subject was taught:

“No, because if you say to your friend they might tell somebody else”. – Primary school response

“Maybe the students do not want anyone to know what is going on in their personal life? Disrespectful as others might talk about it? Too much sympathy from others. - gets treated differently.”

(Secondary school response)

Appendix G – Guidance for bereavement policies in school

These included:

- **A quiet space to go** when they were feeling overwhelmed, sometimes with a chance to talk to someone.
“i was able to go in a quiet room and do some colouring/mindfulness”. (16/17 year old)
- **Time out of class** within the school day when feeling overwhelmed, including on difficult days such as anniversaries, or when the topic of a lesson was painful.
“she had special permission to leave the classroom if she needed to”. (5-12 year old)
- **Flexibility** including extra time to complete work, allowing parents to attend during the day to help with separation anxiety, leeway with late/absence policies including on difficult days such as anniversaries, allowing young people to access specialist support in school hours.
“at school, my teachers gave me extra time to do work so i was less stressed.” (13-15 year old)
- **Provision of resources** such as colouring or story books to help with memories
- **Careful management of information** including informing relevant staff so there is a consistent approach, and letting the rest of the class know.
“they also made sure that her class mates knew what had happened.” (parent of 5-12 year old)
- **Sensitivity around special occasions** such as mothers’ or father’s day.
“on special occasions the school work with my children with regard to cards etc.” (parent of 5-12 year old)
- **Sensitivity when corresponding with** home e.g. Around who invitations are addressed to.

Appendix H – Briefing for the UK Commission on Bereavement

The following briefing was developed for the UK Commission on Bereavement ahead of the public calls for evidence. The briefing acts both as a guide for both the written and oral evidence collected from organisations and as an anchor to the social and economic reality that bereaved people face. It was published on the Commission’s website ahead of the call for evidence and informed the Commission’s thinking around the four key themes investigated in the evidence:

- **Public attitudes and engagement** – including exploration of how employers, schools and other community organisations could better support people who have been bereaved.
- **Practical bereavement support** – including how support could be better provided with administration of tasks after bereavement, and the financial support needs of people who have been bereaved.
- **Infrastructure and intervention** – including the capacity of the sector to assess need, deliver services, and to coordinate between services in order to deliver holistic support to people who have been bereaved
- **The impact of the pandemic** – including the unequal impact of the pandemic on different groups of people who have faced bereavement, and innovations in practice which could provide lessons for the future.

In the report *Bereavement is Everyone's Business*, the Commission then developed the eight key principles, and related recommendations, found in the evidence as a result of the questions in this briefing.

Public attitudes and engagement

Public attitudes across diverse communities to grief, bereavement, support and help-seeking

Several studies reviewing public attitudes towards death, dying and bereavement highlights strong evidence²⁶ that death remains a difficult topic for discussion, which affects attitudes towards grief and bereavement and can act as a barrier to people accessing bereavement support, both from professional services and friends and family. Ongoing national research with people bereaved during the pandemic has found that people still felt uncomfortable about reaching out for help²⁷, despite larger numbers of people needing the support²⁸. Campaigns aimed at raising awareness of death, dying, grief and support are useful, although assessing the impact of these campaigns is challenging. A review by the [Joseph Rowntree Foundation](#) highlights effective elements of campaigns that change public attitude, which could be useful for the bereavement sector.

Capacity of communities and existing social networks (including schools and employers) to support grieving members

Employers need clear guidance and support to help their employees manage the impact of grief and bereavement. Publications provided by business support organisations during the pandemic have highlighted the need for compassion alongside clear policy²⁹. Recent attempts to influence and legislate for minimum bereavement leave indicates the discretionary 'compassionate leave' often offered may not be fit for purpose. [Parental Bereavement Leave](#), introduced in April 2020, offers two weeks leave due to the death of a child under the age of 18, while [Sue Ryder's campaign](#) is aiming to extend this type of bereavement leave for partners or a close family member.

Schools have a dual role to play in promoting emotional well-being around bereavement. Around 1 in 29 school-age children and young people (age 5-16) have been bereaved at some point in their childhood of a parent or sibling – roughly one per class³⁰. Given the numbers of children who will experience bereavement during childhood, there is a strong case for them to learn about some of the common feelings associated with loss. The inclusion of loss and bereavement within a PHSE curriculum can help to dispel myths and taboos, although there no current standard for teaching these topics. Child bereavement charities have responded by developing PHSE lessons around bereavement and loss³¹, although it could be argued that a whole school approach is needed: proactive and flexible pastoral support, a system for managing and communicating important information about bereavements, staff training and support, and policy development³².

²⁶ Several surveys about public attitudes to death and bereavement can be found at in the Reference section of this briefing.

²⁷ Harrop E., Farnell D., Longo M., Goss S., Sutton E., Seddon K., Nelson A., Byrne A., Selman L.E. ['Supporting people bereaved during COVID-19: Study Report 1'](#), 27 November 2020. Cardiff University and the University of Bristol. (Pre-print)– 27% of people surveyed felt unable to ask for help and support beyond friends and family.

²⁸ Harrop E., Farnell D., Longo M., Goss S., Sutton E., Seddon K., Nelson A., Byrne A., Selman L.E. [Supporting people bereaved during COVID-19: Study Report 1](#), 27 November 2020. Cardiff University and the University of Bristol. (Pre-print)– Excess deaths over COVID-19 would suggest that 2.6 million people have been bereaved during the pandemic.

²⁹ Examples of guidance can be found in the Reference section of this briefing.

³⁰ CBN produces regular [statistics](#) although no official data is collected annually on the number of children whose parent dies, nor those bereaved of a sibling or someone else close.

³¹ [Child Bereavement UK](#), [Winston's Wish](#) and [Sudden](#) all have lesson plans and other resources.

³² CBN offers a [whole school approach](#).

Public attitudes and engagement - Key questions for exploration:

- **To what degree are public attitudes to grief, bereavement, support and help-seeking a barrier to effective interventions for people affected by bereavement?**
- **What could help to improve public attitudes to bereavement and the support needs of people who have been bereaved?**
- **How could community organisations – such as employers and schools – better support people who have been bereaved?**
- **Should all health and social care staff have training in bereavement awareness and support?**

Practical bereavement support

Planning ahead and preparing for death and bereavement

Planning ahead and preparing for death and bereavement remains an uncomfortable task, with the number of people who have not made a will appearing consistently high³³. This results in bereaved family and friends having to sort out legal and financial matters, as noted below. There are regular campaigns aimed at the general public to raise awareness and highlighting the positives of being prepared, including [Dying Matters](#), [Demystifying Death Week](#), [Free Wills Month](#) and the [Plan If](#) website, but evidence of the impact of these campaigns on people's preparedness is limited. The pandemic may have prompted a change in attitude for some people³⁴, but it is too early to confirm if this will be a lasting change.

Within healthcare systems, Advanced Care Planning ('ACP') supports better outcomes in bereavement³⁵, although uptake of ACPs across the UK are concerningly low³⁶. The recently relaunched [Ambitions Partnership for Palliative and End of Life Care](#) includes a statement noting that 'good care involves bereavement'. The campaign '[What Matters Conversations](#)' aims to reframe Advance Care Planning to include those elements that matter most in people's lives, including their family and friends.

Administration and practical tasks following a death

The administration and practical tasks, particularly in dealing with the deceased's affairs, can be a long and painful process. There are a number of specific organisations to support this, although the replication of similar services indicates that this area lacks a unifying approach. The government's [Tell Us Once service](#) can allow you to report a death to most government organisations in one contact. This service is usually signposted during the registration of the death. For other services including banks, building societies, media companies, insurance companies, there are at least three schemes that you can use: the [Death Notification Service](#), [Life Ledger](#) and [Settld](#).

Cruse's campaign [Bereaved Customers First](#) is working towards better treatment for all bereaved customers. Settld also wants to ensure that this process is as easy as possible, and along with Cruse, Sue Ryder and Marie Curie, are calling on the government to introduce a [new set of agreed standards](#) for commercial service providers.

Financial impact of bereavement (to include funeral poverty, social security, employment)

The Government reformed bereavement benefits in 2017, when Widowed Parents Allowance - a benefit that offered continuity of income - was replaced by Bereavement Support Payment (BSP), a short-term grant offering payments over 18 months. There is concern that BSP does not provide enough financial relief for families³⁷.

³³ Separate research from [2017](#) and [2020](#) report the same statistic, while there is [no publicly held information](#) about the numbers who die intestate in the UK.

³⁴ Wealth Advisor, '[Thirty one million adults don't have a will in place says new research](#)', 28 September 2020, Accessed 1 July 2020

³⁵ Detering KM, Hancock AD, Reade MC, Silvester W. '[The impact of advance care planning on end of life care in elderly patients: randomised controlled trial](#)'. BMJ. 2010 Mar 23;340:c1345. DOI: 10.1136/bmj.c1345. PMID: 20332506; PMCID: PMC2844949

³⁶ Knight T, Malyon A, Fritz Z, Subbe C, Cooksley T, Holland M, Lasserson D '[Advance care planning in patients referred to hospital for acute medical care: Results of a national day of care survey](#)'. The Lancet, 19 January 2020, DOI: 10.1016/j.eclinm.2019.12.005

³⁷ Internal study conducted by CBN and WAY Widowed and Young, 2020

Additionally, there are other groups who are currently ineligible for bereavement benefits: in particular those who were living with but not married to their partner. A Remedial Order to resolve this is due before the 2021 summer recess. Other cohorts of concern include the children of divorced parents, whose non-resident parent dies, and those who have no recourse to public funds and therefore cannot claim higher rate BSP because of the necessity of being eligible for Child Benefit.

Finally, [funeral poverty](#) highlights the increasing cost of funerals in the UK – with 9% of families unable to meet the full cost of a funeral in 2020. This additional financial stress may compound the experience of bereavement, including feelings of guilt and shame for failing to provide a meaningful tribute to the person who has died.

Practical bereavement support - Key questions for exploration:

- **How could people be better supported to put in place practical plans for death and bereavement?**
- **How could people be better supported to deal with administrative tasks on behalf of the deceased?**
- **What changes are needed to financial support in order to ensure that people affected by bereavement do not face financial hardship?**
- **What flexibility do bereaved people need from employers in order to better support them after the death of a loved one?**

Capacity of health, social care and other services to support bereaved people

There is a strong intention to provide appropriate support for bereaved people as they pass through health and social systems. The [Bereavement Care standards](#), developed in 2014, offer a clear approach for NHS and voluntary services. The voluntary sector has also provided clear frameworks for bereavement support: earlier projects by [Hospice UK](#) proposed a framework for bereavement assessment and more recently, the sector responded to COVID-19 with [resources](#) to support bereavement services. The [National Bereavement Care Pathway for Pregnancy and Baby Loss](#) offers nine standards including that [a parent-led bereavement care plan](#) is in place for all families. Take up of the voluntary pathway has been encouraging, with 63% of English NHS Trusts adopting the pathway. A similar bereavement care plan for families is found in Together for Short Lives' [Core Care Pathway for Children and Young People](#).

With useful frameworks in place, it falls to the bereavement sector to highlight capacity and outcomes. However, despite concerted attempts to focus on outcome reporting, this remains patchy and the sector as a whole does not present consistency around outcomes or effectiveness. There are no nationally collated figures for those who use bereavement services, with the [VOICES survey](#) not recommissioned after 2015. Additionally, questions repeatedly arise around key elements of bereavement support including the timing of said support, cost effectiveness versus effectiveness of delivery and equity of access. As highlighted below, equity of access is of real concern for people who have been least well served.

Finally, many bereavement services operating in the third sector rely on fundraising and volunteers to ensure both capacity and security of support. Before the pandemic, this was manageable but the impact of social distancing and lockdown measures has negatively impacted bereavement services ability to be self-sufficient. A third of managers of bereavement services surveyed in 2020 expected income to drop by 25% or more³⁸ – resulting in the potential withdrawal or reduction in services against an expected rise in demand.

Access to bereavement support

³⁸ NBA, [COVID-19: the response of voluntary sector bereavement services](#), 2020, p. 23

Before the pandemic, between 20 and 30% of bereaved adults were not getting the emotional support that they would like from organised services - beyond their family and friends^{39,40}. There is evidence that those in greatest need may be more reluctant to seek help⁴¹. National monitoring data on access to bereavement services for particular groups is lacking, but evidence from similar health and social care services (palliative care and mental health services) suggest that there are particular barriers to accessing support for those from ethnic minority communities^{42,43,44,45}.

This lack of access has a number of causes. First, people may not be aware of the concept of bereavement support, or of the services that are available. While some services reach out proactively to bereaved people, others rely on self-referral or referral from third parties such as registrars, funeral directors, GPs and family members. The signposting websites AtALoss.org and the Good Grief Trust have helped improve awareness of services in recent years but many people still struggle to hear about support of the type they want.

Second, even where services are known and wished for, there are other barriers to access and the following can exclude people from getting support, both in the early days of grief or later on as the initial shock and disruption eases:

- the stigma of seeking support
- the lack of provision of targeted and specialist interventions
- limited catchment areas
- long journey times
- referral procedures
- waiting lists (particularly for 1:1 support)
- restrictions on the number of sessions

Coordination between agencies supporting people affected by bereavement

As outlined in previous sections of this note, people who have experienced bereavement may have many different but simultaneous support needs – including emotional, social and practical support. As a result, support is often provided by different services at the same time. Good coordination and engagement between services is critical – not least to minimise the number of times someone who has experienced bereavement needs to tell their story. However, often (and partly related to the capacity of the sector) coordination between different agencies is poor. There is a real need to review what could be done at both a local and a national level to improve interagency working and to ensure that people affected by bereavement are provided with holistic support to address the different challenges they face.

“Infrastructure and intervention” - Key questions for exploration:

- **To what degree is funding for the bereavement support sector sufficient to meet the needs of bereaved people, and sustainable into the future?**
- **What can be done to better assess the support needs of people who have been bereaved?**
- **What can be done to better promote access to services – particularly for those groups who have been least well served?**
- **and to promote access to services – particularly for those groups who have been least well served?**
- **How could services be better coordinated to better meet the holistic needs of people affected by bereavement?**

³⁹ Around 20% of people who register a death say that they would have liked to talk to someone about their feelings about the illness or death, but they did not get this chance. 13.3% did get to speak to someone, and 66.3% had not wanted to (Office for National Statistics [National Survey of Bereaved People \(VOICES\)](#) 2015)

⁴⁰ Sue Ryder found that only 9% of the adults they polled about their experiences of bereavement in the last 5 years had received any support aside from that provided by family or friends. 31% of those who did not receive any formal support said that it would have been helpful⁴⁰ (i.e. 28% of those who had been bereaved). Sue Ryder ([A better grief](#) 2019).

⁴¹ Lichtenthal WG, Nilsson M, Kissane DW, Breitbart W, Kacel E, et al. [Underutilization of mental health services among bereaved caregivers with prolonged grief disorder](#). *Psychiatr Serv*. 62: 1225–1229. (2011) doi: 10.1176/appi.ps.62.10.1225

⁴² Calanzani, N., Koffman, J., & Higginson, I. J. [Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK](#) (2013) London: Marie Curie

⁴³ Bignall T, Jeraj S, Helsby E and Butt J [Racial disparities in mental health: literature and evidence review](#) (2019) London: Race Equality Foundation

⁴⁴ Baker C [Mental health statistics for England: Prevalence, services and funding](#) Briefing paper 6988 (2018) House of Commons library

⁴⁵ Mayland CR, Powell RA, Clarke GC, Ebenso B, Allsop MJ [Bereavement care for ethnic minority communities: A systematic review of access to, models of, outcomes from, and satisfaction with, service provision](#). *PLoS ONE* 16(6): e0252188. (2021) doi.org/10.1371/journal.pone.0252188

The impact of the pandemic

Challenges

COVID-19 has impacted bereavement in several significant ways. Firstly, there has been an increase in the number of unexpected and complex deaths. Risk factors associated with poor bereavement outcomes, such as traumatic deaths and social isolation, are heightened due to COVID-19 and associated social and clinical restrictions⁴⁶, meaning that the usual proportion of bereaved adults who are likely to need more support than their family or friends can provide will be higher. In usual times, this is estimated at 40% of the general population of bereaved people but 55% of those bereaved unexpectedly. In the national survey of people bereaved during the pandemic in the UK, only 29% felt adequately supported by friends and family⁴⁷. People bereaved by COVID-19 have higher levels of grief in the first six months of their bereavement than those bereaved of other natural causes – levels that are similar to those bereaved of unnatural causes. Acute grief in the first six months is a predictor of complicated grief further down the line⁴⁸.

Additional challenges for those bereaved during COVID-19 are known to include disrupted rituals⁴⁹, thwarting of social support including isolation and loneliness, economic pressures for families, grief at a time of general fear and a lack of capacity in services, in particular for delivering in-person support.⁵⁰

Inequality

The National Bereavement Alliance ('NBA') identified four priority groups who were most at risk in terms of poor bereavement outcomes during the pandemic. This included:

- those from Black, Asian and other minority ethnic communities (B.A.M.E) communities, and certain occupational groups
- those groups **facing the greatest impact from social distancing**, including those who live alone following their bereavement, or who lack support
- those groups who **already faced barriers to accessing bereavement support prior to the pandemic**, including those from B.A.M.E communities, children and young people, those with a learning disability, those experiencing homelessness
- those **facing particular risks in their bereavement**, including those whose finances are insecure; those facing multiple, sudden and/or traumatic bereavements; and those who have pre-existing mental or physical health difficulties.⁵¹

Innovation

In surveying voluntary bereavement services, recent surveys⁵² highlighted how services had adapted in response to the challenges posed by lockdown measures and social distancing including: developing services specifically for those in early bereavement, establishing new telephone support lines, adapting 1-1 services online or via telephone as necessary, adding content and functionality to websites, including integrating services such as GriefChat function, and widening access to existing services, for example extending support following specific causes of death to include COVID-19.

Additional innovations were seen in the rapid development of high-quality psychoeducational web and print information on bereavement e.g. on self-care, supporting bereaved children, and supporting grieving friends during

⁴⁶ Harrop E., Farnell D., Longo M., Goss S., Sutton E., Seddon K., Nelson A., Byrne A., Selman L.E. [‘Supporting people bereaved during COVID-19: Study Report 1’](#), 27 November 2020. Cardiff University and the University of Bristol. (Pre-print).

⁴⁷ Harrop E., Farnell D., Longo M., Goss S., Sutton E., Seddon K., Nelson A., Byrne A., Selman L.E. [‘Supporting people bereaved during COVID-19: Study Report 1’](#), 27 November 2020. Cardiff University and the University of Bristol. (Pre-print)

⁴⁸ NBA, [COVID-19: the response of voluntary sector bereavement services](#), 2020, p. 16

⁴⁹ Mayland C, Hughes R, Lane S, McGlinchey T, Donnellan W, Bennett K, Hanna J, Rapa E, Dalton L, Mason SR [Are public health measures and individualised care compatible in the face of a pandemic? A national observational study of bereaved relatives' experiences during the COVID-19 pandemic](#), Palliative Medicine, 31 May 2021, <https://doi.org/10.1177/02692163211019885>

⁵⁰ Harrop E., Farnell D., Longo M., Goss S., Sutton E., Seddon K., Nelson A., Byrne A., Selman L.E. [‘Supporting people bereaved during COVID-19: Study Report 1’](#), 27 November 2020. Cardiff University and the University of Bristol. (Pre-print)

⁵¹ NBA, [COVID-19 19: the response of voluntary sector bereavement services](#), 2020, p. 18

⁵² Pearce C, Honey JR, Lovick R, *et al* [‘A silent epidemic of grief’: a survey of bereavement care provision in the UK and Ireland during the COVID-19 pandemic](#) BMJ Open 2021;11:e046872. doi: 10.1136/bmjopen-2020-046872

the lockdown; and significant public facing campaigns around collective national activities on grieving and remembrance⁵³.

Technology

As indicated above, technology has been used proactively as a resource and platform for voluntary sector bereavement services during the pandemic. Commonly described positives around the use of technology included accessibility for certain groups, although the impact on privacy and confidentiality during lockdown restrictions and home-schooling impacted others' ability to join virtual support sessions. For example, those home-schooling children during lockdown or working in shared offices,⁵⁴ while support for children and young people has not necessarily benefitted from using technology and some people in later life are also digitally disconnected

"The impact of the pandemic" - key questions for exploration:

- **To what degree have new challenges emerged as a result of the pandemic, and to what degree has COVID-19 exacerbated existing problems?**
- **To what degree have different social groups – including BAME communities, and those living in poverty - been affected differently through the course of the pandemic?**
- **Have models of good practice emerged during the pandemic which should be retained and further developed in the future?**
- **What has been the impact of new approaches to technology use in supporting people affected by bereavement through the pandemic?**
- **Is there more that needs to be done to prepare for future mass bereavement events like COVID-19?**

⁵³ NBA, [COVID-19 19: the response of voluntary sector bereavement services](#), 2020, p. 20

⁵⁴ Harrop E., Farnell D., Longo M., Goss S., Sutton E., Seddon K., Nelson A., Byrne A., Selman L.E. [‘Supporting people bereaved during COVID-19: Study Report 1’](#), 27 November 2020. Cardiff University and the University of Bristol. (Pre-print)

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- Sue Ryder, [‘A Better Grief’](#), 2019. PDF file

Guidance for employers

- [COVID-19: The impact on death, bereavement and grief – Business in the Community](#)
A toolkit which provides guidance for employers on developing an empathetic, compassionate and inclusive response to death, bereavement and grief, and for businesses to support their employees in expressing and sharing how they feel.
- [A guide to compassionate bereavement support: general guidance – Chartered Institute for Professional Development](#)
A guide which provides some key tips for organisations on how to support employees who are dealing with a bereavement in the short and the longer term.
- [A guide to compassionate bereavement support: guidance for line managers – Chartered Institute for Professional Development](#)
A guide, specifically for line managers, which provides some key tips on how to support employees who are dealing with a bereavement in the short and the longer term.
- [How you can help your employee after their child has died – Care for the Family and Bereaved Parent Support](#)
A series of suggested ‘dos and don’ts’ for employers supporting employees that have experienced the bereavement of a child.
- [Our NHS People: Understanding different bereavement practices and how our colleagues may experience grief – NHS](#)
Guidance for employers regarding different bereavement practices and how to support employees appropriately.
- [Time off for bereavement – ACAS](#)
Guidance for employees for when a bereavement happens, particularly around leave, pay and the benefits of firms having a bereavement policy.

 Follow the conversation @theukcb

The UK Commission on Bereavement works alongside the following organisations:



National Bereavement
Alliance



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

