

Help when the worst happens



**An urgent report on meeting the needs of people
bereaved in challenging circumstances**

A COVID-19 recovery response and beyond, June 2020

Sudden
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Contents

Preface	2
What is a challenging bereavement?	3
A rising tide of challenging bereavements	4
Avoidable deaths	5
Multiple bereavements for every death	6
Who is most likely to suffer a challenging bereavement?	7
Shock reactions	10
Poor outcomes if needs are neglected	12
Help after a challenging bereavement	17
The Sudden Services	26
Four urgent recommendations	27
Bibliography	28

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In the evening dad was in his bedroom saying he felt 5 out of 10 in terms of sickness, and we were getting him glasses of water, and the next morning my mum told me he was dead.

”

Teenage girl on the death of her father, at home from COVID-19, BBC, April 2020

Preface

There is an opportunity for good to come out of this pandemic; to give people bereaved in challenging circumstances the support they deserve and need.

This report aims to shine a light on those challenging circumstances, the poor outcomes that bereaved people in these circumstances can suffer if not supported, and appropriate support.

There is no time to lose. As this report outlines, in 2020, due to COVID-19, people are being bereaved in challenging circumstances in far greater numbers. Charities and health experts are rightly calling for an urgent focus on funding and development of provision of bereavement support.

Support starts from day one and through the early weeks of a challenging bereavement, when needs can be acute and threaten health and safety; and also in later months and according to need, for example support with grieving and mental health.

Without support, we know people bereaved in challenging circumstances can suffer a range of poor outcomes that negatively affect them, their families, community and our economy.

With support, provided in evidence-based, timely and straightforward ways, people are more likely to move forwards into a positive future.

This report calls for bereavement and support charities, health and social care agencies, community leaders, and government to work with urgency, together, to secure these futures for the sake of us all and in the name of humanity.

Mary Williams OBE



Mary is chief executive of Brake and Sudden. Brake runs the acclaimed National Road Victim Service, a service that cares for people bereaved or suffering life-changing injuries as a result of road crashes. Brake also hosts Sudden, a service that cares for people bereaved in any challenging, usually sudden, way, including by COVID-19.

What is a challenging bereavement?

Every bereaved person can benefit from support.

There are certain challenging circumstances that are more likely to result in a bereaved person needing more support, and more specialised support. These challenging circumstances mean it is harder to cope, grieve and move forwards into a positive future.

Five challenging circumstances are:

- 1 Shock** when someone dies suddenly or after only a brief illness.
- 2 A loss of future life and shared plans**, particularly when someone dies as a baby, child, young person, or mid-life adult.
- 3 A loss of care provided by a person who has died**, for example a parent, guardian or partner of any age who provided significant support including emotional, financial and practical.
- 4 Pre-existing vulnerabilities of a bereaved person**, for example, illness, disability, poverty, and social exclusion, for example due to a language barrier.
- 5 The time we are living in.** COVID-19 means we are all vulnerable. Fear and physical distancing rules means we are all at risk of feeling stressed, unsupported, and isolated. We are also not able to say goodbye, in normal ways, before or after any death.

A challenging bereavement could be due to:

a medical cause, such as COVID-19 or another rapidly-advancing disease, or one of many unexpected medical causes, such as a stroke, heart attack, or a neo-natal or stillbirth;

an event, such as a road crash, a work-place incident, homicide, alcohol/drug poisoning, or terrorist attack;

suicide.

A rising tide of challenging bereavements

Pre-pandemic, there were more than half a million deaths a year in the UK (616,014¹ deaths in 2018 according to the Office of National Statistics (ONS)), with the biggest causes of deaths expected (for example, dementia).²

Sudden deaths may be doubling, or possibly more, in the UK in 2020 due to COVID-19.

Not counting some deaths that are expected or occur for comorbidity reasons, a preliminary, probably cautious estimate of sudden deaths, in pre-pandemic times, could be c.50,000 a year or more² (see Avoidable Deaths)). At the time of writing, COVID-19 deaths had risen above 40,000.

It is therefore not unreasonable to estimate that sudden bereavements in 2020 could be c.100,000 or higher, out of total deaths likely to be 660,000 or higher.

This means perhaps 1 out of 7 deaths in 2020 will be sudden deaths (or 1 in 6 if pandemic deaths continue to rise significantly), while in normal times they are probably around 1 in 12 deaths (a still significant number).

More deaths happen “too soon”, including deaths of children, young people and mid-life adults from cancer.



Sudden deaths may be doubling or more in 2020 in the UK, inclusive of deaths from COVID-19.

1 in 7 deaths (c.100,000 out of 660,000) or more may be sudden deaths, compared with 1 in 12 in normal times.

Many more deaths happen “before people’s time”, for example some cancer deaths.

Avoidable deaths

Some deaths are classified by the Office of National Statistics (ONS) as avoidable through prevention (eg road crashes) or treatment (i.e. disease).

In 2018, approximately 22% of all deaths in the UK were considered avoidable (138,293 deaths out of 616,014).⁴

ONS groups these deaths into categories. These categories include; respiratory diseases, infectious diseases, circulatory diseases, injuries, and alcohol and drug related deaths.

Avoidable death (ONS, 2018) ⁵	No. of deaths
Circulatory disease (eg strokes, heart attacks, etc)	36,900
Infectious disease (eg. sepsis, meningitis, etc)	2,139
Respiratory disease (eg pneumonia, flu, respiratory infections, etc)	18,653
Injuries (eg due to suicide, road death, homicide)	10,106
Alcohol or drug related (including accidental and as a method of suicide)	13,897

ONS records a further c.48,000 deaths as avoidable neoplasms (including cancers).

These categories include deaths of people of all ages.

It is not possible from the ONS data to know how many deaths defined as avoidable occurred suddenly.

Conversely, it is likely that some deaths that are due to an unexpected cause are in other data sets. (For example, deaths resulting from major injuries but possibly not recorded as avoidable because the death happened months or even years later.)

It is possible that some types of sudden death (for example road death, suicide) may increase or decrease in 2020 due to reasons related to the social impacts of COVID-19, but any changes are impossible to speculate and unlikely to have a presiding effect on the estimated totals.

Multiple bereavements for every death

For every death, there are many more people bereaved.

Bereavement affects parents, partners, siblings, children, cousins, grandparents, aunts, uncles, friends. It impacts colleagues at work, classmates in our schools, and people in our communities, clubs, faiths.

An average household size in the UK is under 3 people.⁶ However, this varies significantly and many of us live apart from people we love (for example, parents of adult children). It is reasonably estimated that, on average, at least 5 people⁷ feel very close to someone who has died suddenly (members of an immediate family) and perhaps a further 20 people or many more feel they are bereaved (for example grandparents, cousins, close friends).

Using these estimates, 100,000 sudden deaths in 2020 would mean:

about 500,000 people suffering a sudden bereavement of a very close family member.

many more suffering a bereavement that happens too soon in life, for example by cancer.

Sudden bereavement may happen to more than half a million close family members in 2020 in the UK.

Many more people will be bereaved by a death that has happened in early or mid-life, for example some cancer deaths.



Who is most likely to suffer a challenging bereavement?

Some people are more likely to suffer one or more challenging bereavements.

Some people bereaved in challenging ways are more likely to have vulnerabilities, either pre-existing or arising as a consequence of bereavement.

Older people facing isolation

Older people, for example those bereaved by COVID-19 due to the death of a partner, may find themselves living alone, sometimes coping with their own illnesses, including for example COVID-19 infection and pre-existing conditions affecting older people disproportionately (for example dementia).

Such factors can pose immediate health and safety risks, particularly if combined with isolation due to physical distancing.

Families, children and young people

Some bereavements are at the heart of family life, for example the death of a parent who provided care or income, or the death of an active grandparent who cared for children, or the death of a child or young person.

Any death of a child or young person from any cause, or any child or young person who is bereaved, is considered by psychological trauma experts to be a challenging bereavement.

ONS figures for England in 2018 tell us that while half (51%) avoidable deaths were people over the age of 70, half were younger.*

Some of these are sudden and horrific. Children and young people under the age of 35 are more likely to be victims of murder than older people.⁸ The biggest killer of young people is suicide.⁹

Age of death is important because it can be a contributory factor (one of many) to the impact of a bereavement on people. (It should be stressed, however, that different deaths at different ages cause different impacts depending on circumstances, including isolation among older people if their partner dies suddenly.)

* Avoidable mortality, Table 5: Number of avoidable, treatable and preventable deaths by sex and 5-year age group, England, 2001 to 2018^{1,2,3}

Social deprivation

Some people dying from COVID-19, or from some other medical causes that happen suddenly, or before old age, have pre-existing health vulnerabilities that are also linked to social deprivation, including, for example, diabetes, cardiovascular disease and obesity.¹⁰

Children living in more deprived communities are more likely to be at risk of certain deaths than wealthier children. For example, they are more likely to be killed in a road crash¹¹ than children in wealthier communities.

This means people bereaved suddenly or suffering the death of someone too young also have a heightened risk of suffering social deprivation at the same time (for example, low or no independent income housing problems, etc.)

Ethnicity

People from Black, Bangladeshi and Pakistani, Indian, and Mixed ethnicities have been disproportionately affected by COVID-19 in the UK than people of white ethnicity.¹²

Concerns have been raised that this may be partly due to social inequalities, such as crowded housing conditions due to poverty.

People from Black and south Asian ethnicities, and people from deprived backgrounds, are also at higher risk of strokes and at higher risks of strokes happening earlier in their lives.¹³

Some people in Black, Asian and Minority Ethnic Communities face additional challenges, including for example language barriers.

Multiple bereavements, injuries and other vulnerabilities

Some people are suffering multiple bereavements, either at the same time, or within a short space of time, one or more of which may be challenging for numerous possible reasons.

Some people suffer challenging bereavements as a result of an event (such as a road crash or terrorist attack) that also causes non-fatal, but life-changing injuries in a family (for example, paralysis, brain injury or limb loss) that bring additional and very significant challenges.

There are a range of other pre-existing vulnerabilities that can make bereavement more challenging. For example, domestic violence, split families, addictions.

People with physical and mental illnesses

Coping with a challenging bereavement while also coping with chronic illness is very challenging indeed.

People with physical illnesses includes, for example, people with COVID-19, people with dementia, and people going through cancer treatment. There are many other examples that could be listed.

It also includes people suffering pre-existing mental illness inclusive of anxiety and depressive conditions.

Disabled people

Some disabled people may face increased challenges and change at a time of sudden or premature bereavement, particularly disabled people with physical disabilities or learning disabilities who received care from someone who has died.

People with particular disabilities may be disadvantaged in particular ways during bereavement, for example people with profound hearing loss are excluded from access to phone-based help.

Physical distancing and isolation during COVID-19

During COVID-19, physical distancing rules has affected all bereavements.

Before death Many people, particularly those bereaved by COVID-19, have not been able to be by the side of a loved one who is dying.

After death Normal post-death rituals involving spending time with a body have been prevented in cases of COVID-19. Funerals and other ceremonies have been affected by conditions including limited size of gatherings of people.

Some bereaved people facing isolation (due to physical distancing, living alone or no family or friends they feel able to call upon) may struggle to access bereavement support, even over the phone or online, because they don't know it exists, or hearing is impaired, there is a language barrier, they do not have access to the internet, or they cannot seek help for themselves, for reasons such as shock or illness.

Shock reactions

People bereaved suddenly, either from a medical cause or an event, commonly suffer shock reactions. They have no or very limited time to prepare, either emotionally or practically, for life without the person who has died.

Shock reactions can be immediate, unfamiliar, frightening, and unsettlingly changeable and unpredictable, both in when they occur, their duration and their severity.

In families, reactions experienced are likely to differ from person to person and happen at different times, making family dynamics challenging too.

Shock reactions can include all kinds of things. Reactions, and their severity, depend on the person, their circumstances, and the circumstances of the death or deaths they have experienced. Some shock reactions are listed here.

A range of extreme emotions that may change from day to day, or even minute to minute. These emotions may range from desperation, to overwhelming sadness, to extreme fear, to anger and regret, and many more.

Problems communicating coherently or engaging in conversation. A person in shock may not be able to speak at all or behave very out of character, for example shouting or screaming.

Feeling frozen and disconnected from reality, unable to retain information and remember important and basic things that need doing. A person in shock may find it difficult to move or do anything at all. They may be unable to undertake the most basic tasks, or find such tasks very challenging and slow, such as getting dressed, or making a cup of tea. They may struggle to notice and react to risks, such as a hot pan, or approaching traffic. They may forget to care for their own basic human needs or those of others around them, such as the needs of children.

Physical reactions, including inability to sleep or eat a full meal. They may suffer physical pain or other symptoms, such as feeling sick, feeling very cold, or suffering tremors or shaking.

“

I found myself sitting on a bench, unable to move, and shaking horribly. I was all alone, cold, it was dark and I hadn't eaten for two days. I will never forget that night and I was lucky to get home safely. Looking back, I simply was not caring for myself, and no-one else was caring for me. I hope other people get the help they need.

”



Poor outcomes if needs are neglected

Physical neglect and injury

Someone facing a challenging bereavement may not be able to articulate their needs nor be able to care for their own, or others', basic human needs and health and safety. This includes simple things, such as staying warm, eating, take medicine, and staying away from danger. Physical well-being is threatened and can easily deteriorate, through neglect or injury or both.

A person facing a challenging bereavement may feel their own welfare is unimportant.

Becoming traumatised

If left without support, people bereaved who are suffering from shock or other major challenges may suffer continual, mounting distress and find themselves in distressing situations, due to inability to care for their own wellbeing or, in family situations, inability to care for each other well.

This may result in the days and weeks after a death feeling chaotic, out of control, and a time of fear and panic. This period can therefore be traumatising, in addition to any traumatising effect of the bereavement itself, or events leading up to the death.

There is evidence¹⁴ that lack of support for people following an event that can be traumatising is a pre-indicator of poor mental health outcomes. Mental health conditions may also be less likely to be identified as they arise and left untreated, becoming chronic and affecting people more severely, for longer.

Deterioration of care of dependents

People suffering a challenging bereavement and left unsupported may be less likely to care for others effectively. This means vulnerable dependents, such as older people with health conditions, or children and young people, may suffer consequential neglect, while also often suffering themselves as a result of the sudden bereavement.

“

I remember feeling so worried about everyone else, particularly the children. I forgot that it is important to get your own oxygen mask on before you try to help others fit theirs. I wish I had received more support for me in the early days, so I could have helped those around me better.

”

Unclaimed entitlements

People who are bereaved in challenging ways often have entitlements available to them.

This can include, for example: government-provided benefits and funeral payments, time off work, compensation if the death was caused by a preventable event or medical neglect, or a right to have their voice heard in a criminal court case (for example through a victim statement).

When someone is bereaved in challenging ways, and not supported, they may find it harder, or impossible, to find out about, or access, entitlements. Entitlements are there for a reason; to protect wellbeing. Without this help, wellbeing can deteriorate.

Inability to grieve

Grieving when someone dies is a normal process and involves a normal range of emotions, particularly sadness. It is an important part of moving towards a new and positive future.

People bereaved in challenging circumstances may find it much harder to grieve the death of their loved one, within their families or their social circles. They may find it hard, for example, to even think about, or talk about, a death.

People bereaved in challenging circumstances may find it harder to participate in grief support services, nor find them useful, due to complexities they are facing and/or their level of distress, particularly if services are not specifically tailored to meet the needs of people bereaved in similar ways.

Negative impact on people trying to help

Neighbours, mutual aid groups, GPs, care home workers, teachers, faith workers and many others want to help people who are bereaved in challenging ways. Community help can be invaluable, particularly help meeting health and safety needs, such as collecting groceries and medicines, and help that demonstrates kindness, such as taking the time to listen to someone in distress.

However, people trying to help, with no experience or skills in doing so, may need help providing the best possible care, that does not cause harm to them or others. They may suffer vicarious trauma (be traumatised by the experience of trying to help). They may suffer moral injury (blame themselves for doing or saying something to a suddenly-bereaved person that they subsequently consider was wrong, for example if the suddenly-bereaved person subsequently kills themselves).

“

I recently heard of a child whose parent died on the Friday, and on the Monday was sent back to school and invited by a teacher to join a group counselling session with other children. It was well-meaning, but entirely inappropriate.

”

Mental health nurse

Poor mental health outcomes

Bereavement and grief is not a mental illness. However, bereavement in challenging circumstances can cause poor mental health outcomes.

There are a number of disorders that have been diagnostically defined and can occur consequential to a challenging bereavement. This includes Prolonged Grief Disorder¹⁵ and Persistent Complex Bereavement Disorder.¹⁶

Such disorders are often called “complicated grief”.¹⁷

Research¹⁸ has found a ‘significant association’ with disorders and overall levels of grief, as well as depression.

Post-Traumatic Stress Disorder (PTSD)¹⁹ is one possible, and serious, poor mental health outcome for people bereaved suddenly in challenging circumstances and traumatised by the death itself, and in some cases traumatised by additional events either before, or after, the death.

PTSD symptoms can include:

- re-experiencing what has happened or avoiding thinking about something
- hypervigilance, anger, irritability
- negative moods and thinking
- feeling emotionally numb and disassociated
- not being able to manage emotions
- interpersonal difficulties or problems in relationships
- feeling negative, defeated, worthless²⁰

Appropriate treatment for poor mental health outcomes following a challenging bereavement often includes talk-based therapy delivered by professionals experienced in helping people who have been suddenly bereaved and who have been traumatised.

Early identification of symptoms and treatment is important to enable timely treatment and quicker recovery, consequently lowering the chance of poor life outcomes such as loss of employment, family breakdown, suicide.

“

Deaths due to COVID-19 are associated with risk factors which can lead to prolonged grief disorder, post-traumatic stress, and other poor bereavement outcomes, as well as moral injury and distress in frontline staff [in hospitals].

”

Bristol Medical School, University of Bristol²¹

The economic cost of sudden bereavement

Bereavement in challenging circumstances can cause mental health outcomes resulting in significant economic burdens on the individual, health and social services, and employers. Research on the economic cost of sudden bereavement is limited. However, existing research on one mental health outcome, PTSD, allows an illustration of just how significant these costs can be.

The direct costs of PTSD from COVID-19 deaths alone in the UK in 2020 could be between £11m and £43m or much higher, with total costs (direct and in-direct) of between £101m-£168m or much higher.

The calculations to estimate these costs (given below) provide a very conservative estimate of the impact of mental health disorders due to COVID-19 bereavements. The actual costs incurred are likely to be magnitudes higher as a result of

- a) the development in different people of one of a number of different disorders (such as Prolonged Grief Disorder), not just PTSD; and
- b) many more people than just one being affected per death and therefore many more susceptible to disorders.

The calculations are based on:

- 50,000 deaths in the UK in 2020, due to COVID-19
- 5.2% of people develop PTSD following the unexpected death of a loved one (Koenen KC, Ratanatharathorn A, Ng L, McLaughlin KA, Bromet EJ, Stein DJ, et al., 2017) (5.2% of 50,000 bereaved people (one bereaved person per death) is 2,600 people)
- Available research findings regarding the average costs of PTSD per person suffering it:
 - £4,362.45 for service use (direct) costs and £60,266.62 for indirect costs (Fuckkan Buljan, 2015)
 - £16,616 for direct costs and £22,268 for indirect costs (Ferry et al., 2015)

Provision of case managed care for people affected by a challenging bereavement enables timely identification of warning signs of a disorder, and consequential signposting to assessment and treatment of a disorder, meaning less suffering and lower costs, particularly the more expensive, indirect costs. Provision of care in the early days and weeks has also been shown to result in better outcomes for people.

“

In the early days after my bereavement, I was told to apply for grief counselling but there was a waiting list. I found that unacceptable because I was in such distress but was not offered anything else by my GP other than anti-depressants, which I did not feel was appropriate. I was bereaved not mentally ill!

I plucked up the courage to join a local grief support group and went to a meeting. The person next to me told me it was a friendly, social group where we could share our stories and support each other through our grief.

I am sure they were lovely people helping each other, but at that time I was suffering far too deeply.

I increasingly felt anxious and overwhelmed.

I also felt the people there would not understand the horror of how I had been bereaved and what I was going through, right then.

I couldn't cope, so I left quickly.

”

Help after a challenging bereavement

Unsurprisingly, the proportion of bereaved people needing more support than family and friends is significantly higher among people bereaved in challenging circumstances.²²

It is important to ensure everyone, whether they are facing isolation, live alone or are in a family, gets the help they need.

The bad news is that there are many people bereaved in challenging ways unlikely to be getting help they need, due to a lack of funded and appropriate service provision. Charities and health academics are supporting a mounting collective voice that this lack of funding and service provision must be remedied.

“

Given the current COVID-19 pandemic, there is an urgency from a public health perspective to expand bereavement services in an attempt to mitigate poor bereavement outcomes, including prolonged grief disorder and other psychiatric disorders.²³

”



The good news is that there is significant evidence about how to help people bereaved in challenging ways. Help should be accessible, meet needs, collaborative.

Help for people bereaved in challenging ways should be:

- 1 Accessible**
- 2 Meet needs**
- 3 Collaborative**

1 Accessible

To access bereavement services, people need to first know about them.

People in shock and with other vulnerabilities understandably struggle to research services and understand how they may be able to help.

People in communities can play an important role to achieve accessibility. Hospital staff, coroner's office staff, funeral directors, police, GPs, lawyers, faith groups and mutual aid groups can:

- learn about services – what they offer and who they are for;
- give bereaved people information (digital and printed) about services;
- organise referrals to these services.

During COVID-19, both Sudden, and the Good Grief Trust, have called for a focus on enabling bereaved families to access bereavement support services. A paper written for hospital clinicians also calls for this to happen “as soon as possible after the patient's death”.²⁴

2 Meet needs

Support for people bereaved in challenging ways must be tailored to an individual's circumstances.

Sudden has categorised nine crucial needs that must be met in the development of service provision for people bereaved in challenging ways. Services must:

- i. **identify** people with elevated risks and work to “safeguard” these people (for example people with suicide risk) from day one onwards;
- ii. **provide emotional support for people suffering shock**, in particular help understanding shock reactions, help finding coping mechanisms for whatever shock reactions people are facing at whatever time, and help supporting others in a family who are also facing shock. A trauma-informed approach should be taken (see Trauma-informed approach);
- iii. **provide support with acute practical needs in the early days** to sustain health and safety, for example, shopping for food, providing meals, or collecting medicine;
- iv. **provide timely access to urgent entitlements**, for example, help with paying for a funeral, housing costs, and access to benefits, etc;

- v. **provide specialist support, depending on circumstance, and in a timely way**, for example, early and on-going help for bereaved children and young people, people with disabilities/ illnesses needing care, people with addictions, or people suffering a bereavement that involves specific procedures, eg. a post-mortem examination, inquest, police investigation (for example murder, road death, suicide);
- vi. **provide help as needed with other paperwork and legalities**, for example, registering a death, wills and probate, stopping mail, finding a lawyer to help with a specialist claim for compensation, etc;
- vii. **provide “active monitoring”**, sometimes referred to as “watchful waiting”, to identify persistent or emerging reactions that could be a sign of a mental disorder that can be subsequently assessed and treated, for example as a result of the bereavement being traumatising;
- viii. **signpost grief support services** at an appropriate time, according to the circumstances of a person and their bereavement, for example grief support services that are specialist to a particular type of bereavement (eg suicide) or more general (for anyone bereaved);
- ix. **monitor progress towards well-being outcome goals** to inform any further care provision required, and to inform service development.

Trauma-informed approach

Not everyone bereaved in a challenging way is traumatised by their bereavement or events preceding or after their bereavement. However, some people, understandably, are traumatised.

Good practice support for people suffering a challenging bereavement can, in many ways, mirror support that is considered helpful to people who have experienced a traumatic event (for example, a major disaster or terrorist attack).

Trauma experts²⁵ talk about “stabilisation” (meeting essential needs), “education and normalisation” (helping people understand trauma and that what they are going through is normal), and agreeing appropriate support needed for the person and getting it (including from their pre-existing support networks as well as specialist or community agencies).

The outcome is to ensure safety, restore choice and control, connect people to enable support, and help people to cope and build resilience (people’s coping mechanisms and ability to cope may vary day to day).

The gaps in service provision

Some people bereaved in certain challenging ways are, helpfully, automatically referred to expert support provision within hours (for example, homicide, road death, and suicide services are particularly referred into, often by the police).

Level of support provided is however dependent on funding of the agencies providing the support (with homicide services receiving significant funding at present).

However, many other people bereaved in different but also challenging ways report not knowing where to turn, or being given incorrect information about help, and consequently suffering disappointment, isolation and unmet needs.

For example, people bereaved in challenging ways often report that soon after their bereavement they

were given details of grief support services that they then found to be inappropriate for them or unavailable at the time they needed help.

Most commonly, people report being given information about grief support services that are designed to be accessed only after a couple of months or longer have passed, and designed for anyone bereaved by any cause and not for people suffering their particular type of challenging bereavement.

Consequently, support may be not provided at all for people bereaved in challenging circumstance.

Alternately, people within communities without the necessary specialism may provide some aspects of care really well such as providing meals or healthcare, but are very unlikely to meet all needs, and risk their own welfare being damaged.



3 Collaborative

Effective support from day one of a challenging bereavement onwards should be tailored to an individual person's circumstance and needs and achieve outcomes that contribute to their wellbeing. Often this means a pathway of care that is collaborative, meaning it utilises more than one agency and service. This includes:

- **Helplines for people in crisis,** particularly those with extended opening hours. Calls are typically anonymised. Helplines can improve access to services by referring callers on to specialist agencies.
- **Information, printed and online,** explaining reactions to challenging bereavement, and giving advice on a whole range of issues to meet needs. Information can also improve access to services by listing specialist agencies.
- **Up-skilled community partners.** Hospital staff, police officers, GPs, social and child/youth workers, mutual aid groups, faith groups and many other organisations and people in communities can all help. They can help by: understanding challenging bereavement and knowing about, and referring into, correct specialist bereavement services; providing practical support, particularly in the early days with shopping etc; acting in ways that are compassionate. There is

evidence that compassionate help from community partners can help people.²⁶

- **Case management from a named support worker.** This is thought by many to be a 'gold standard' aspect of support for people bereaved in challenging ways, from day one onwards. It is offered by the Sudden Service and services for homicide victims and road death victims. A named bereavement support worker is assigned from day one to: safeguard and identify needs as they arise; provide a range of support to meet those needs; coordinate provision of support from partner specialist support services or general grief support services too as appropriate over time to further meet those needs (see below); and monitor and evaluate a bereaved person's progress and overall wellbeing (if necessary utilising clinical help from a mental health professional), to a point when the person being helped can be determined to no longer require case managed care (see Case Management in Practice).
- **Specialist support services,** either provided by nationally or locally by charities or by health or social services. For example, services for bereaved children, families and widowed partners (for example Winston's Wish, Child Bereavement UK, and WAY Widowed and Young), services for people who have suffered particular kinds of bereavement (for

example, suicide charities) and services for people with particular disabilities or vulnerabilities such as addictions. Sometimes, there are often a range of different services provided by one agency. Some examples include:

- Helplines and face-to-face support
- One-on-one bereavement counselling courses (either over the phone or in person, with a limited number of sessions provided);
- Group-based services, for example, online meet-ups, chat forums or local meetings in community centres, etc;
- Social-based events, for example day trips and holidays;
- Courses, workshops and other learning events;
- Opportunities to “do something to make a difference” as a group, for example fundraise or campaign for change to stop certain deaths.
- **Support services set up to care for people suffering any kind of bereavement** often with a focus on grief support, often after a few months have passed since a bereavement. These services also often offer helplines, one-on-one counselling or listening services, and group-based services. A national example is Cruse.



- **Mental health services**, providing assessments and treatment, often in the form of talk-based therapy, if someone bereaved is thought to be suffering a disorder or condition. These services are available through the NHS and privately. Some charities provide access to these services.

Hug in a Hamper

Some specialist services offer unique, creative and low-cost services as part of their other services and that demonstrate compassion and community care. An example is Pete's Dragons, a Devon-based suicide support service that distributes hampers at Christmas to families bereaved by suicide.

Case Management in Practice

Case management means being assigned a professional, named support worker, who works face to face or over the phone, to provide and coordinate support, from day one until no longer necessary.

A case management approach is provided by the National Homicide Service (run by the charity Victim Support) for people bereaved by murder, and the National Road Victim Service (run by Brake, the road safety charity) for people bereaved by road death. Such an approach means–

- Continuity of care from a named person, building trust and stabilising;
- Safeguarding (obtaining immediate support if someone's wellbeing is at risk, for example they are suicidal or ill);
- Identification of needs and wellbeing goals including acute and more long-term, and a pathway planned to meet these goals;
- "Active monitoring" of mental health, so any deterioration can be addressed in line with health recommendations;
- Emotional support, harnessing help from other agencies as appropriate, for example health and social care providers, specialist charities and mutual aid groups;
- Access to additional services if desired, for example peer-led grief support from people bereaved in the same way or from support workers, either in a group setting or one to one (face to face or online);
- A managed exit, identifying whether wellbeing goals were met and if so, how, and any outstanding goals that require signposting for help elsewhere;
- Monitoring and evaluation, helping service development and helping to set standards across the bereavement sector.

Support workers in a case management service operate best in a managed structure, within an organisation that cares for their welfare (through supervision, clinical debriefing, and peer support) enabling support workers to stay in role for a longer time, gaining further expertise and skills and further helping, and not "burning out" or suffering moral injury.

Case management following homicide and road death

Two case management services are referred into by police following homicide and road death.

Homicide: The need to provide case managed care of people bereaved by homicide in England and Wales was recognised at the end of 2018 when the Ministry of Justice announced significant funding (£6.8m for 2019-2021)²⁷ for the **National Homicide Service (provided by the charity Victim Support)**, saying this case managed service was to remedy *“increasingly arbitrary divisions of bereaved families into different support arrangements, depending on geography and date of bereavement.... Families’ needs are not dictated by location or time. They can be lifelong and recurring, and must be supported as fully as possible, consistently.”*²⁸

Road death: Central funding from the Department for Transport and regionally from Police and Crime Commissioners also supports the **National Road Victim Service (provided by Brake)**, which provides case management in a similar way to the Homicide Service. One feature of this service is its high quality, annually-reviewed information packs for bereaved families, which mean families can be helped, with the assistance of their designated support officer at Brake, to understand a range of complex procedures that follow road death and help children.



“If it hadn’t been for Brake, I would never have found out about the bereavement group near me, and when the time was right, thanks to your help, I would never have been encouraged to go along. It helped me meet some incredible folk who I still am friends with now. We shared feelings and they didn’t judge me.”

“Bereavement is a journey. Brake was there for me, every step. To talk to and open up to. You helped me so much.”

Pandemic responses in 2020

During COVID-19 there has been a heightened awareness of a lack of funding for care for people bereaved in challenging ways, particularly in the early days of bereavement. Recognition of this problem has resulted in a pandemic response from a range of agencies and charities.

- **Sudden**, previously a respected project promoting best practice care of people bereaved in sudden ways, extended its work to provide a service for people bereaved suddenly including by COVID-19 (see next page).
- **NHS Blood and Transplant** and the **National Bereavement Partnership** set up pandemic bereavement helplines with extended opening hours.
- The **National Bereavement Alliance** led a call from the sector to government to fund services responding to bereaved people in the immediate aftermath and over the weeks and months following their bereavement.
- Other charities, including those previously only helping people bereaved in particular ways, for example the cancer bereavement charity **The Loss Foundation**, broadened services to help people bereaved by COVID-19.
- The **Good Grief Trust** has produced cards carrying helpline numbers that can be given to bereaved people by officials such as hospital staff.



The Sudden Service

The Sudden Service, a phone-based case management service for anyone bereaved by any sudden or otherwise challenging cause of death, has been set up as a pandemic response by the charity Brake, and is working to achieve funding to deliver at the highest level and continue beyond the pandemic.

The Sudden Service builds on a project by the same name which has been run by Brake for many years to disseminate expert opinion from academics and practitioners on how best to care for people bereaved in sudden circumstances.

Sudden Service support officers taking calls say that callers to the service are describing reactions that are intense shock reactions, and that callers are seeking immediate support within the first days and weeks of bereavement from COVID-19, but also from other sudden causes such as stroke and suicide.

Support officers are working with callers to normalise their reactions, help them establish coping mechanisms, and address immediate and urgent practical needs, working in partnership with specialist services.

“Everything is upside down. Nothing seems normal or even true. I feel I am losing my mind.”

“I am so glad you are here, I can’t talk to anyone, particularly not my family.”

“I can’t believe it. I can’t accept it. I can’t picture a future. It’s all too painful.”

“We both went into hospital, but only I came home. I couldn’t even see the body.”

“I feel strangely numb. I can’t feel anything yet.”

“All of a sudden, I am a single parent.”

“I can’t sleep or eat.”

“I feel so guilty. I survived but I probably passed on COVID-19 to them, and they died.”

“How can life ever be the same again?”

“I was also bereaved last year. Now I feel I am going backwards.”

Anonymised quotes from callers to the Sudden Service, May 2020

Four urgent recommendations

- 1. Charities and others providing bereavement helplines, case management services, specialist services for people bereaved in challenging ways and grief support services should work to ensure that clients have a pathway of care from day one that protects health and safety and wellbeing.** This includes having a duty of care to:
 - a. safeguard, protecting vulnerable people's health and safety;
 - b. collaborate with each other to ensure distinction and understanding of roles and enable referrals between agencies, and into mental health services as appropriate;
 - c. work towards, and monitor and evaluate, wellbeing outcomes for clients, sharing learnings about service development and set standards.
- 2. Government, at national and regional level, should undertake a cross-department review of services funded,** seeking to provide equitable funding provision for services that:
 - a. support bereaved people most typically facing challenges;
 - b. are evidence-based against wellbeing outcomes.
- 3. Government, as part of COVID-19 recovery, should provide emergency funding for charities providing bereavement support,** particularly those working in the ways described above, and who have been hit hard by reductions in charitable giving.
- 4. Community partners, including hospitals, primary health and social care providers, mutual aid groups, faith leaders, and employers, schools and clubs** should train and enable staff/volunteers to help bereaved people appropriately and within their remits, and to refer bereaved people to correct support in a timely manner.

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Sudden is hosted by the charity Brake.

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