

Commissioning for Compassionate Community Bereavement Support

Introduction

The COVID-19 pandemic has not only exacerbated challenges around bereavement, it has also spotlighted this universal human experience, presenting a rare opportunity to consider how well equipped we are to support people through a bereavement, and how we can work together to improve that support both now and in the future.

UK Commission on Bereavement, 2022

Good palliative and end of life care includes giving care and support to families, friends, carers and all those who are important to the dying person. This must encompass good bereavement and pre-bereavement care, including for children and young people. It must also respond to the needs of those who are affected by death caused by sudden illness or trauma, including suicide.

Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026

Bereavement is a universal experience – a natural part of a life lived in relationship and community. But how we experience grief varies from person to person, and over time. Bereavement can touch many aspects of our lives: our health, our relationships, our identity, our finances, our living arrangements and so much more.

Many of us will manage the disruptions of bereavement with our own inner resources and the support of family and friends. But often we can feel lonely, misunderstood and overlooked, and troubled by difficulties sleeping, eating, concentrating and getting on with life. Some of us will need additional support at times in our bereavement, perhaps help with getting back to work, or making sense of our overwhelming emotions, or taking on responsibilities carried out by the person who died.

Because so many different people are involved in providing bereavement support, from close family friends and neighbours through community groups to organised and statutory services, it can feel disjointed and difficult to get the help we need.

The impact of the pandemic

Pre-existing difficulties with getting support in bereavement were made so much worse by the tragic loss and life and social restrictions of the COVID-19 pandemic. Hundreds of thousands of extra bereavements happened in the most difficult of circumstances, with many of us prevented from saying goodbye to loved ones, gathering to console one another, and getting support.

During the pandemic, many local areas worked together to respond to the unprecedented needs of bereaved people. Neighbours found ways to memorialise those who had died and to support lonely widows and widowers, despite not being able to gather together as they usually would.

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Funeral directors found ways to support people to plan meaningful funerals, even when numbers were severely restricted. Bereavement groups switched to meeting online. Individual counselling and support sessions were delivered by video call. Services worked together to develop local Single Points of Access to join up the support available to bereaved people. Bereavement networks formed to share training and develop referral pathways across services.

How things could be different

It is crucial that we learn from and build on these innovations. There is so much more that we can do to join up and enhance support in local areas. Two key recent changes provide a framework to help us do this.

- New arrangements for better partnership working between health and care services and communities, introduced by the Health and Care Act 2022, provides an important opportunity to do things differently, and better. These provide new structures and ways of working for local people, communities and services to collaborate to set out a vision for bereavement support in the local area, and to work together to make this vision a reality.
- The work of the independent UK Commission on Bereavement set out in detail the challenges that bereaved people face across every aspect of life. The Commission set out 8 principles for change: the things that we would like all bereaved people to be able to say, with clear recommendations to help bring these changes about.

Despite these opportunities, there are few examples of bereavement support being prioritised at the level of Integrated Care Partnerships. It is possible that more activity is happening at the level of place or local authority.

Bereavement in Integrated Care Strategies

We reviewed 42 Integrated Care Board websites and local council websites to find published Integrated Care Strategies (ICSs), with a view to seeing how bereavement was positioned at systems level across England. We identified 36 ICSs during February and March 2023.

Only 9 of these (25%) had any reference to bereavement. These references comprised

- mention of significant commitments to bereavement resources and cultural appropriate resources but no strategy about how this would be implemented was available. A case study on a childhood bereavement service was also featured.
- 'Dying Well' as a key workstream priority, including bereavement care, with reference Bereavement Improvement Plans.
- provision of robust bereavement services for all with a Palliative and End of Life Care sub-strategy.
- a specific suicide postvention service as a case study and noted annually surveying bereaved carers to see if end-of-life care need were met.
- mention of bereavement as an issue affecting 'many' in the Case for Change, along with a commitment to specific support for children and young people dealing with adverse childhood experiences, including bereavement; and an acknowledgement that bereavement affects mental health.
- a commitment to ensure there was awareness of and appropriate services for those bereaved by suicide
- mention of improving bereavement support and service within a specific locality, as well as a focus under a mental health strategy Northamptonshire
- acknowledgement of residents' requests to provide bereavement support
- reference to bereavement as an example of the impact of Covid-19 on mental health.

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Despite the paucity of specific mentions of bereavement, we identified many other opportunities where bereavement could have been included.

- 22 ICSs (61%) were organised around a life course approach, of which 8 (22%) included a 'Dying Well' or similar element
- 16 ICSs (44%) included a reference to palliative or end of life care, and 13 mentioned hospices
- 29 ICSs (81%) mentioned death or dying, largely in the context of mortality statistics, commitments to reduce early or preventable deaths, or learning from deaths. Of these only 6 mentioned death in the context of dying, death and bereavement.
- 22 strategies (61%) mentioned Covid-19 but none of these mentioned the impact of Covid-19 on increased mortality or bereavement. Common themes that emerged included: stresses on health systems, stresses on people (mental health), innovation/collaboration and community focus as a result of the pandemic.
- Almost all strategies (94%, n=34) mentioned the importance of mental health in some way. This area of health is a clear concern and priority for many ICBs. Only one strategy specifically mentioned bereavement as an additional factor that could impact mental health (through the lens of the pandemic).
- 25 strategies mentioned loneliness (and/or social isolation and the impact that these can have on both mental and physical health. However, there was no explicit acknowledgement that bereavement can be a cause of social isolation in later life.
- Carers were mentioned in 29 strategies (81%), with an overwhelming majority recognising the importance of unpaid carers as essential to supporting those with health and care needs, including young carers. There were various initiatives for carers including a Carers Strategy, a Carers Partnership Board, an All Ages Carers Strategy, a Carers Partnership Group, and the Worker Carers Passport Initiative. There was a consistent theme of involving carers in decision making and an acknowledgement that carers may be in poor health themselves, and have their own health and care needs.

About this guidance

To support systems and places to prioritise bereavement support, the National Bereavement Alliance has produced this suite of guidance and resources for commissioners and providers of bereavement services.



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Overall, we hope these will help communities, providers and commissioners collaborate to ensure that the full range of bereavement support is in place and integrated, following expected and unexpected deaths across an Integrated Care System or place-based partnership.

Commissioning for integrated bereavement support spans the responsibilities of health and social care across end-of-life care, carers' support, maternity services, mental health services, suicide postvention, emergency preparedness, emotional wellbeing and services for specific groups. Commissioners in these different spheres will need to work creatively together to identify local needs and ensure these are met, by communities, non-commissioned and commissioned services. Comprehensive frameworks exist for commissioning specific aspects of bereavement support, including end of life care, support following suicide, and support following pregnancy loss or the death of a baby. This suite of resources complement these by providing an overall approach.

The table below summarises the key elements making up this guidance. These can all be accessed from <https://nationalbereavementalliance.org.uk/ourpublications/commissioning/>

Title	Element
The impact, risks and costs of bereavement	Summarises the impact and risks of bereavement, and the societal costs that these bring including increased ill health, early mortality and use of medications and health and care services
How bereavement contributes to health outcomes frameworks	<p>Sets out how the risks of bereavement and the benefits of support are relevant to</p> <ul style="list-style-type: none"> • The NHS Priorities and Operational Planning Guidance • The Public Health Outcomes Framework • The Adult Social Care Outcomes Framework
The policy context for commissioning bereavement support	<p>Identifies the national policy documents that mention bereavement or are relevant to bereaved people, across</p> <ul style="list-style-type: none"> • General health frameworks • Palliative and End of Life Care • Support for carers • Support for mental health • Support following a death • Support following a suicide • Support following homicide • Support for wellbeing (children and adults) • Support for loneliness
What should be available in each area	Outlines the three-component model of integrated bereavement support, and what each Integrated Care Partnership should ensure is in place in the area.
Identifying local needs and mapping support and gaps	<p>Provides guidance on how to ensure that support is tailored to specific local needs. Includes</p> <ul style="list-style-type: none"> • Involving bereaved people in service design • Using publicly available data on local needs

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	<ul style="list-style-type: none">• Mapping existing support and identifying gaps.
Getting bereavement on the agenda locally	<p>Summarises ways in which bereaved people and bereavement services can champion bereavement support, including</p> <ul style="list-style-type: none">• Getting bereavement included in local health and care strategies including the Joint Strategic Needs Assessment, Joint Health and Well-being Plan, Integrated Care Plan and Joint Five-Year Forward Plan• Raising bereavement as an issue in the run-up to local and national elections• Working on a council motion.
Are we getting it right? Guidance for assessment and evaluation	<p>Identifies how to use monitoring, evaluation, assessment and outcome tools to improve bereavement support.</p>

Feeding back

We aim to keep these resources up to date as new learning and policy frameworks emerge. We are also keen to get feedback from those using the resources.

Please complete our feedback form to share your thoughts and suggestions.

<https://www.surveymonkey.co.uk/r/MTXYCDD>

Acknowledgements

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www.nationalbereavementalliance.org.uk

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