National Bereavement Alliance

Commissioning for Compassionate Community Bereavement Support

What should be available in each local area

This guide sets out what components of bereavement support should be available in each area. This includes support provided by family, friends, communities, commissioned and non-commissioned services.

The guide forms part of a suite of resources for commissioners and providers of bereavement services. These resources are intended to build on the opportunities in the Health and Care Act 2022 and the UK Commission on Bereavement. 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.

Overall, 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 partnerships.

To see the full suite of resources, visit
https://nationalbereavementalliance.org.uk/ourpublications/commissioning/

Introduction

Many people will manage the challenges of bereavement – their distress and the further changes it brings – with the support of family and friends and from the wide range of professionals and organisations they may encounter in everyday life. The Bereavement Care Pathway (Cruse Bereavement Care and Bereavement Services Association, 2014) maps the breadth of organisations that are in a position to support people around a death.

Some bereaved people will need extra help, beyond that which their family, friends and existing social networks can provide. Flexible, non-stigmatising, commissioned support at multiple levels helps communities to respond adequately, and provides more intensive help to those who need it. This support may be commissioned across a range of services including end of life care, carers' support, maternity services, mental health services, suicide postvention, emotional wellbeing and services for specific groups. Commissioners also need to plan to respond at every level to meet the needs of communities affected by local disasters and incidents. The COVID-19 pandemic brought huge challenges to bereaved people and those providing and funding services and the learning from this is invaluable in planning for future pandemics.

Commissioning bereavement care can also bring significant gains in social value: additional benefits to the community over and above the direct purchasing of goods or services. Public health approaches to bereavement support including the use of volunteers can bring benefits

including peer support, reduced isolation, and the normalizing of dying, death and grief. Together, these can strengthen networks and build the capacity of communities to support bereaved people (Rumbold and Aoun, 2014).

Each Community is Prepared to Help: Guidance on Ambition Six (National Council for Palliative Care, 2016) sets out how health and social care organisations can use community development approaches as a routine part of their provision of end of life care, and Public Health Approaches to End of Life Care (National Council for Palliative Care, 2015) identifies practical approaches to building compassionate communities.

The three-component model and the public health approach

The National Institute for Clinical Excellence set out a three-component model of bereavement support in its Supportive and Palliative Care for Adults with Cancer (2004), based on a systematic review of the evidence available at the time. The End of Life Care Strategy (Department of Health, 2008) applied this model to all expected deaths. No similar model exists for sudden deaths.

Since 2004, the research and the experiences of those using, providing and commissioning bereavement services have added to the body of evidence around levels of need and components of bereavement support. In addition, the NICE model has been complemented by a public health approach, which maps the three components on to a universal/targeted/ indicated model of tiered support. The public health approach emphasizes the capacity of social networks and communities to respond to bereaved people, and positions bereavement care as a shared responsibility between communities and healthcare services (Rumbold and Aoun, 2014). This model fits well with the opportunities for increased partnership working and community involvement, put on a statutory footing by the Health and Care Act 2022.

We have adapted these models to accommodate this additional learning and new thinking.

- Family, friends and existing networks will continue to provide much of component 1 support, with information being supplied by health and social care professionals providing day-to-day care to families.
- We have divided component 2 services between those promoting mutual help and those providing structured support from trained and supervised people.
- We have divided component 3 services into two sections, to distinguish between interventions provided by specialized bereavement counsellors/practitioners and those provided by mental health services. People may need component 3 services because their grief is complex and they are showing symptoms or risks of complicated or prolonged grief; and/or because they have clinically diagnosable mental health conditions alongside or triggered by their bereavement.

The interdependence of the components

The opportunities for increased joined working brought about by the Health and Care Act 2022 gives commissioners and providers the ability to collaborate and combine resources towards a joint vision for bereavement support within a local area. This will include support from friends, families and communities, along with commissioned and non-commissioned services.

Details of what support should be available for each component are set out in the table below. Although the components are described as being distinct, in reality they overlap. These components do not all need to be provided by one organization, but services do need to be

integrated sufficiently for bereaved people and their supporters to understand what is available, to whom, and how to access it.

The three components are interdependent. Without the resources of component 1 and the opportunities for component 2 support, component 3 services would be overwhelmed by people unable to find less intense support, and whose difficulties either may not warrant counselling or therapy, or have escalated because of the lack of easily available support. Without component 2/3 services there would be nowhere to signpost people in greater need, overwhelming friends and families' capacities to support and straining health services that may lack the resources to respond.

The support outlined can be provided in a range of accessible modes including face to face, telephone and online, depending on assessed needs and choice. The challenges of providing bereavement support during the pandemic has contributed to major innovations through the development of apps, podcasts, books and online resources, as well as the acceleration of phone and online support. A choice of delivery modes is welcome but services must ensure they are accessible to all that need them, including those who are digitally excluded.

Cultural considerations in the delivery of bereavement support are paramount (UK Commission on Bereavement, 2022). At all components, bereavement support and services should ensure that they are committed to tackling inequities in experiences of bereavement and access to support.

What should be available in each local area

Tier/component	Type of support	Target population and level of need	Support provided by	What the Integrated Care Partnership needs to ensure is in place
Public health: Universal NICE component: 1	Information about bereavement and sources of support	All bereaved people Low level of need	Verbal, written and on-line information provided by professionals involved in end of life care, registrars and others providing day to day care to families	• Accessible and accurate information on practical issues and on grief, including details of local and national services including those at components 2 and 3, with details of how to access these • Community capacity building to raise awareness of grief, how to help, and when to seek extra support • Bereavement training for health and social care professionals coming into regular contact with people facing or living with bereavement • Commitment to partnership approach to meet bereavement support needs
Public health: Targeted NICE component: 2	Non-specialist support	Some bereaved people Those seeking support or at risk of developing complex needs	2.1 Social support: self-help groups, faith groups, befriending and community groups	• 1:1 and group opportunities for support, including for specific groups of bereaved people e.g. children and young people, those bereaved by suicide • Leadership, organisational infrastructure and training to support service delivery • Pathways for onward referral to component 2.2 and 3 services • Commitment to partnership approach to meet bereavement support needs
			2.2 Trained bereavement support workers	• 1:1 and group opportunities for support, including for specific groups of bereaved people eg children and young people, those bereaved by suicide • Assessment to determine appropriate level of support

				• Leadership and organisational infrastructure to support the selection, training, coordination and supervision of volunteers and paid staff • Coordination of referrals • Pathways for onward referral to component 3 services if more complex needs emerge • Commitment to partnership approach to meet bereavement support needs
Public health model: indicated NICE component: 3	Specialist interventions	A minority of bereaved people Those with complex needs or prolonged/ complicated grief. High level of need	3.1 Specialist bereavement counsellors / practitioners	• Assessment to determine appropriate level and type of support • 1:1 and group opportunities for specialist intervention, including for specific groups of bereaved people eg children and young people, those bereaved by suicide • Leadership and organisational infrastructure to support service delivery • Clinical supervision • Provision of training to those working in component 1 and 2 services • Commitment to partnership approach to meet bereavement support needs
			3.2 Specialist mental health support / psychological support for those with mental health problems which pre-date or are triggered by their bereavement	• Mental health provision • Clinical supervision • Pathways for referral from component 1, 2 and 3.1 services to specialist statutory mental health support services • Commitment to partnership approach to meet bereavement support needs

The right support for the right people at the right time

Bereavement support comes in many forms and it is important that people and communities are empowered to better manage their health and well-being following bereavement, which includes engaging with the right type of support for them.

Making sure that people are aware of the services available, assessing practical and health and safety needs, vulnerabilities and strengths, and providing early, straightforward support that enables people to feel safe, supported and connected to their community can help reduce some of the risk factors contributing to social deprivation, isolation and mental health difficulties.

Some bereaved people who need support beyond that which their family and friends can provide will benefit from general support (not specialist to bereavement) such as welfare benefits advice or befriending groups. However, these supports and services do need a basic understanding of how grief can manifest itself, and how to be welcoming and supportive to bereaved people. Others will need support that is specific to bereavement.

It is generally accepted that not all bereaved people need routine referral for 1:1 bereavement counselling simply because they have been bereaved (Stroebe et al, 2017). Offering 'counselling' routinely may encourage people to use services rather than turning to family and friends or allowing their grief to follow its natural course. It could encourage people to view grief as a mental health problem per se, rather than a normal reaction to loss which can increase vulnerability. It could lead to the unnecessary over-professionalization of bereavement care.

There is strong evidence that 'bereavement counselling', a term used indiscriminately to describe both component 2 and component 3 services, is more effective if risk factors associated with resilience and vulnerability are used to target services (Schut, 2010; Neimeyer, 2010). Counselling is also more effective for those who self-refer (Wittouck et al, 2011), although those who need services may be reluctant to ask for help (Prigerson et al, 2001).

It is important to distinguish between the demand for information and services and the need for support and counselling. The NICE three-component model and the public health approach emphasize the mechanisms that help get the right help to the right people at the right time.

These include:

- **public education** which helps bereaved people – and those around them – to understand more about grief and when it is appropriate to seek extra help.
- **assessment**, which takes account of people's needs and risks alongside their resilience and strengths, so that they can have help that is appropriate to their level of need. This is particularly important for those who might not seek help themselves, but who are experiencing (or at risk of experiencing) negative outcomes.

Assessing individuals' needs in bereavement

Guidance for bereavement needs assessment in palliative care (Relf et al, 2010) outlines approaches to exploring people's resources and needs. Includes measures that can be used by nurses and other health care staff to assess the needs of people before and around the time of their bereavement. The nine-item Adult Attitude to Grief Scale (Machin, 2007) may be used to assess the needs of those self-referring to bereavement services and is able to identify degrees of resilience and vulnerability. It can be used alongside more generic health and quality of life measures. Other bereavement needs assessment tools have been reviewed for use in specialist palliative care settings (Agnew et al, 2010) and many are equally appropriate for use in community settings with people bereaved through sudden and unexpected death.

See our guide 'Are we getting it right?' for more information about assessment, monitoring, outcomes and evaluationWho needs what type of support?

No official data are collected on the overall number of bereaved people in a given area. Several people may be affected by a death and various multipliers have been used to estimate the total number of bereaved people in the population from the number of deaths in an area. However, care must be taken when using such multipliers to estimate the need for bereavement service provision. This will also be affected by local risk and protective factors. For a fuller description of data sources that can be helpful in contributing to an estimation of need, see our guide to identifying local needs and mapping services and gaps.

Support for bereaved children and young people

The Childhood Bereavement Network has set out the support that should be available in each local area, so that all bereaved children and their families can access high quality support easily, wherever they live and however they have been bereaved (2017). To underpin this support, the local Health and Wellbeing Board and Integrated Care Partnership should work with other services to make sure they know how many children and young people have been bereaved that year, and what services they need. They should also ensure that adults who work with children get training and support to understand how they might help someone who has been bereaved, and where to find extra support.

To play their part, each school should have sensitive and flexible people and systems who provide support and information to children and staff when someone is dying or has died, and opportunities for children and young people to learn about death and bereavement as part of life.

Quality assurance

Users, providers and commissioners of bereavement care need reassurance that services are meeting agreed standards of quality. The Bereavement Care Service Standards (2014) were developed by the Bereavement Services Association and Cruse Bereavement Care, funded by the Department of Health. They comprise fundamental principles and seven areas of good practice, set out in appendix 4. Some sectors have elaborated and expanded the Standards for their own setting, eg palliative care and acute hospitals. Many providers adopt the Standards alongside other professional standards and codes of practice. The Childhood Bereavement Network has produced a Checklist for good practice in services supporting bereaved children and young people (2007), supported by a self-audit tool.

Next steps

This guide has set out the basic components of what should be available in each local area. However, the exact specifications will be determined by local need. Use the other guides and resources in this series to tailor this vision to the local risk and protective factors at system or place level.

https://nationalbereavementalliance.org.uk/ourpublications/commissioning/

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