

A Guide to Commissioning Bereavement Services in England



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bereavement services in England**
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Foreword

When my father died, almost twenty five years ago, nothing could have prepared me for the roller coaster of emotions: the intense sadness and grief, intermingled with an appreciation of joyful memories. The death of someone dear to us is never easy. It brings a host of changes, adjustments and emotions. It is a process that each bereaved person has to go through – nobody else can do it for us, and there is no shortcut.

Many people find sufficient support through their existing relationships and networks and do not need any formal intervention. Others may struggle to find the help they need to deal with the practical challenges of the death and make sense of what has happened. For some people, bereavement can be a distressing, overwhelming and traumatic time. This can have a huge impact on their health and wellbeing, both immediate and longer term.

The first Ambition of the [Ambitions for Palliative and End of Life Care: A national framework for local action](#) – each person is seen as an individual – makes it clear that good end of life care includes support in preparing for, and during, bereavement. Commissioners, providers and staff, in providing care for the person as an individual, need to take into account their unique relationships with their friends, family, carers and community.

People within communities need to be prepared to support each other in times of crisis and loss, emotionally and practically. Ambition 6 in the Ambitions for Palliative and End of Life Care Framework emphasises that commissioners should include public health approaches in their plans, recognising practical support required from local health, care and voluntary organisations. The way in which services, professionals and communities respond to those who are bereaved can have a long term impact on how they grieve, and their health and wellbeing.

Recent tragic incidents in Manchester and London remind us how important it is for communities to have the resources to be able to respond and cope with both expected and unexpected bereavement. It is vital that area-based bereavement services are available for both expected and unexpected deaths. The predicted rise in the annual number of deaths in England of 25% by 2040 (ONS 2015) means that a population based approach is even more critical. Commissioners and local authorities need to have an understanding of local need and what is already available in their area, including through voluntary organisations, so that they can design services that best support the health and wellbeing of local people.

This helpful guide, produced by the National Bereavement Alliance, underlines the importance of bereavement services in influencing the experience of care at the end of life, and reducing long term effects on bereaved people. It helps commissioners address the public health challenges of bereavement through planning for the bereavement support needs of their community, ensuring that people who are grieving are able to access high quality, expert support when they need it.

Professor Bee Wee, National Clinical Director for End of Life Care, NHS England.

Introduction

"I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways."

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020

"Any commissioning plans must encompass good bereavement and pre-bereavement care, including care for children and young people."

The End of Life Care Commissioning Toolkit

This document aims to help commissioners prepare tender specifications for area-based bereavement services for expected and unexpected deaths. Commissioning for integrated bereavement care can be challenging because it spans the responsibilities of health and social care across end of life care, carers' support, maternity services, mental health services, suicide prevention, emergency preparedness, emotional wellbeing and services for specific groups.

Comprehensive frameworks exist for commissioning end of life care and support following suicide, and these are key resources for commissioning bereavement services. This document complements these resources by providing a specific focus on bereavement and bereavement services. It contains:

- an overview of the need for bereavement services
- requirements for local bereavement care
- quality standards and evaluation methods
- an overview of national policy in relation to bereavement services
- appendices mapping bereavement care against the Health and Social Care Outcomes Frameworks.

How to use this guide

As a commissioner

Many different types of commissioners (eg adults and children, specialized commissioners, local authority public health) may hold responsibility for bereavement services. If you are preparing a tender document, we suggest you read the background and requirements sections, and then read the national policy areas that are relevant to your specific circumstances.

As a provider

We suggest you read the requirements section, and then the national policy areas that are relevant for the tender you are preparing. The outcomes frameworks in the appendices will help you to map your work against health and social care outcomes.



Background: the need for bereavement services

Grief is a normal reaction to bereavement and many people find that their inner resources, combined with support from family and friends, are sufficient to help them manage their distress and the life changes and adjustments triggered by loss. However, general awareness and understanding of grief is often lacking, which can leave bereaved people feeling lost and misunderstood. Additionally, bereavement is associated with risks to health and wellbeing and can give rise to a wide range of needs.

Services that can help people manage their grief range from the provision of information through health promoting community-based resources to more intensive, specialist help for those whose reactions are complex or prolonged, and affect their ability to manage everyday life.

The number of bereaved people is growing. The annual number of deaths in England is increasing and is predicted to rise by 20% over the next 20 years (ONS, 2015), alongside increases in the population and a dramatic rise in the proportion of elderly people (Calanzani et al, 2013). As the House of Lords report [Ready for Aging](#) (Select Committee on Public Service and Demographic Change, 2013) highlighted, we are 'woefully underprepared' to meet the challenges of an ageing population. One of these challenges will be the growing number of bereaved people – particularly among the elderly.

What is the impact of bereavement?

Grief is a normal reaction to the death of someone close including partners, babies and children, parents, siblings, other relatives and friends. Although often seen as primarily emotional, grief is multi-faceted with physical, cognitive, spiritual and behavioural dimensions, and it may begin before the death. Some people experience traumatic stress reactions, for example when the circumstances of the death are particularly distressing. For many people, bereavement also brings life changes and practical challenges, including dealing with the administration of the death, assuming new responsibilities and adjusting to and building a new life without the person who died.

Common grief reactions in adults

(Adapted from Relf, 2002)

Emotional

- Depression, sadness, sorrow, despair
- Guilt and remorse re events surrounding loss or past behaviour toward deceased
- Anger re health and social care providers, the deceased, family members, friends, God
- Aloneness – feeling emotionally isolated
- Loss of enjoyment - believing that to experience enjoyment is impossible or wrong
- Relief - that suffering has ended / that role of carer has ended
- Low self-esteem and feelings of inadequacy, failure, incompetence, worthlessness

Behavioural

- Agitation, restlessness, over-activity, 'searching' for deceased
- Fatigue - apathy, poor concentration
- Expressions of sadness
- Changes to patterns of life – e.g. sleeping, eating, libido
- Avoiding or seeking situations that may trigger grief

Cognitive

- Yearning/pining for deceased, pre-occupation, hallucinations, idealisation
- Hopelessness - loss of purpose, loss of hope for the future
- Anxiety – difficulty making decisions, fear re own health, fear re future
- Low self-esteem – feelings of inadequacy, worthlessness
- Sense of unreality and feeling removed from current events

Social

- Relationship difficulties - feeling misunderstood and unsupported
- Feeling lonely
- Managing different grief reactions with family and social network

Physiological

- Loss of appetite, weight change
- Physical complaints - tension, muscular pains, indigestion, shortness of breath, lump in throat, palpitations, panic attacks
- Increased use of antidepressants and other medicines, alcohol, tobacco
- Lowered resistance to infections

Common grief reactions in children

(Dyregrov, 2008)

- Anxiety
- Vivid memories
- Sleep difficulties
- Sadness and longing
- Anger and acting out behavior
- Guilt, self-reproach and shame
- School problems

Some children might show regressive behaviour, social isolation, fantasies, personality changes, pessimism about the future, preoccupation with cause and meaning, and a sense of maturity and growth as a result of being bereaved.

Over time, most adults' grief follows one of three patterns (Bonnano et al, 2011; Mancini et al, 2015).

- **Resilience** with a return to functioning after some months (often, but not always, after an initial period of intense disturbance).
- **Gradual recovery** over a year or more.
- **Prolonged distress**, which may pre-date the death and last for years.

While many people are resilient and regain their equilibrium, a minority experience persistent high levels of distress and chronic grief symptoms that impact on their physical and mental health and on their functioning for a substantial period (Shear, 2015; Prigerson et al 2009). There is debate about the diagnostic criteria for these difficulties, which have been described as prolonged, persistent, complicated or complex. Prolonged grief disorder and complicated grief are collections of difficulties, which are distinct from, but often found alongside, other mental health disorders such as depression, anxiety and post-traumatic stress disorder. Around 10% of bereaved people experience these difficulties (Lundorff et al 2017). Higher rates may be found among specific groups such as parents whose child has died.

Other bereaved people may experience high levels of distress for a shorter period. For example, they may have disturbing memories of the events leading up to the death, blame others for the death or feel remorse for their own behavior.

Following the death of a parent, around one third of children will have clinical levels of emotional or behavioural difficulties at some point over the first two years (Worden, 1996).

The risks of bereavement

Bereavement is associated with an increased risk of mortality, physical and mental health problems (such as anxiety and depression), relationship difficulties and difficulties coping with everyday life. In Appendix 1 these risks are mapped against the NHS Outcomes Framework, CCG Outcomes Indicator Set, Adult Social Care Outcomes Framework and Public Health Outcomes Framework.

These risks are associated with factors including the bereaved person's history, health and sociodemographic variables; the situation and circumstances of the death; the meaning of the relationship with the person who died; the perceived quality of social support and concurrent stressors such as caring for others and housing or financial problems (Stroebe et al, 2007).

Bereaved people make greater use of healthcare services (Stroebe et al, 2007) including GP services, mental health services, acute and psychiatric hospitals, and consumption of medicines. These increases begin before the death, spike immediately after it, and may last for months or years. Some services are used twice as much in the year following the death (Guldin et al, 2012). Bereaved children (Lloyd-Williams et al, 1998) and adults visit GPs more frequently but studies suggest that those with complex or prolonged grief may be less likely to do so (Stroebe et al, 2007).

In Scotland, there is evidence that shows that the death of a spouse is associated with increased mortality and also with longer hospital stays. These longer hospital stays cost NHS Scotland around £20 million each year (Corden, 2013). In England, with over eight times the number of deaths, this figure would be very much higher. It would be even greater if it included the impact of non-spousal deaths such as the death of a child or parent, and if it included the costs of using other health and social care services, and the costs of time off work. It is estimated that at any one time bereavement impacts on one in ten of the workforce (McGuinness, 2009), affecting sickness absence, morale, productivity and retention.

The benefits of bereavement support

High quality bereavement support can help to achieve the outcomes identified in the frameworks in the appendices.

Organised bereavement support can reduce the use of health care services, including GP consultations (Relf, 2000). Full cost benefit analyses of bereavement services are underdeveloped, and this is a priority area for research. However, the unit costs of providing bereavement services can be set against the unit costs of other types of health and social care provision that people might access in bereavement.

Unit costs of health and social care, 2016-17

(Curtis and Burns, 2016)

All ages

- GP consultation of 9.22 minutes: £36
- Social worker (adult or children's services): £79 per hour of client-related work
- Family support worker: £52 per hour of client-related work

Adults

- Improving access to psychological therapies (IAPT) adult and elderly: £96 per care contact
- Mindfulness-based cognitive therapy – group intervention: £173 per session
- NHS community mental health team for older people with mental health problems: £43 per hour per team member
- Home care services for older people or people with mental health problems: £180 per week
- Re-ablement service: £2,131 per service user

Children

- Generic multi-disciplinary Child and Adolescent Mental Health team: £4,895 average cost per case
- Cognitive Behaviour Therapy for adolescents with depression: £97 per 55 minute session
- Common Assessment Framework decision-making panel: £232 per child
- Parenting programme to prevent persistent conduct disorder: £1,233 per parent



Social value and community capacity building

Commissioning bereavement care can 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.

Requirements – what should be available in each local area?

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 to support them. 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 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).

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 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.

Details of what needs to be commissioned to provide support at each component are in the table opposite. 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 support outlined can be provided in a range of accessible modes including face to face, telephone and online, depending on assessed needs and choice.



Public health	NICE component	Type of support	Target population & level of need	Support provided by	What needs to be commissioned to ensure this component is in place?
Universal	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	<ul style="list-style-type: none"> • 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 • Component 2 and 3 services • Bereavement training for health and social care professionals coming into regular contact with people facing or living with bereavement
Selective or targeted	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	<ul style="list-style-type: none"> • 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
				2.2 Trained bereavement support workers	<ul style="list-style-type: none"> • 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

Public health	NICE component	Type of support	Target population & level of need	Support provided by	What needs to be commissioned to ensure this component is in place?
Indicated	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 3.2 Specialist mental health support / psychological support for those with mental health problems which pre-date or are triggered by their bereavement	<ul style="list-style-type: none"> 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 Mental health provision Clinical supervision Pathways for referral from component 1, 2 and 3.1 services

The right support for the right people at the right time

It is generally accepted that people do not need routine referral for 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). In 2015, only one in four of those who wanted to talk about their feelings about their relative's illness or death with someone from a health, social care or bereavement service got to do so (Office of National Statistics, 2016).

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 the need

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.

How many people need what type of support

No official data is collected on the overall number of bereaved people in a given area. Information is available from:

- [The Office of National Statistics](#) on the annual number of deaths in each local area
- [Public Health England](#) on the rates of premature deaths by local authority
- The [Childhood Bereavement Network](#) provides estimates of the number of bereaved children and young people in each local authority 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.

- **Is the multiplier the same as that used in studied populations?** Estimates of what proportion of people need support at which level - including those in the NICE three-component model - are derived from studies of widowed people or 'key carers', generally focussing on one bereaved person per death (Aoun et al, 2015; Ward et al, 2004). These suggest that around 10% of those people needed component 3 support, 30-35% needed component 2 support, and the rest managed with component 1 support. Caution must be used when extrapolating levels of need from these sub-sets of bereaved people to the general population to avoid over-estimating rates of vulnerability.

- **Does the local population have the same needs as the studied population?**
The 2004 NICE guidance focused on supportive and specialist palliative care. This population may have a greater need for support because patients may be younger and have a more complex physical or psychological symptom burden. The risks to health associated with bereavement also reflect general factors such as deprivation, rates of traumatic death (e.g. number of refugees, suicides and homicide rates). Commissioners should take these contextual factors into account when estimating need.

Case study: service use

A specialist palliative care bereavement service gave information to 800 key carers following the deaths of 693 people (1.2 bereaved people per death). 312 people accepted support, of whom:

- 240 (30% of those contacted) received supportive counselling from trained and supervised volunteer bereavement support workers (NICE component 2 services)
- 72 (9% of the 693) received therapeutic counselling from specialist bereavement counsellors (NICE component 3 services)

However, in practice the boundary between the work of specialist, trained volunteers and specialist counsellors is fluid and volunteers may work with people with degrees of complexity.

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). The components of such support are shown in Figure 1 (overleaf).

To underpin this support, the local authority and clinical commissioning groups 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.

Who will need this?

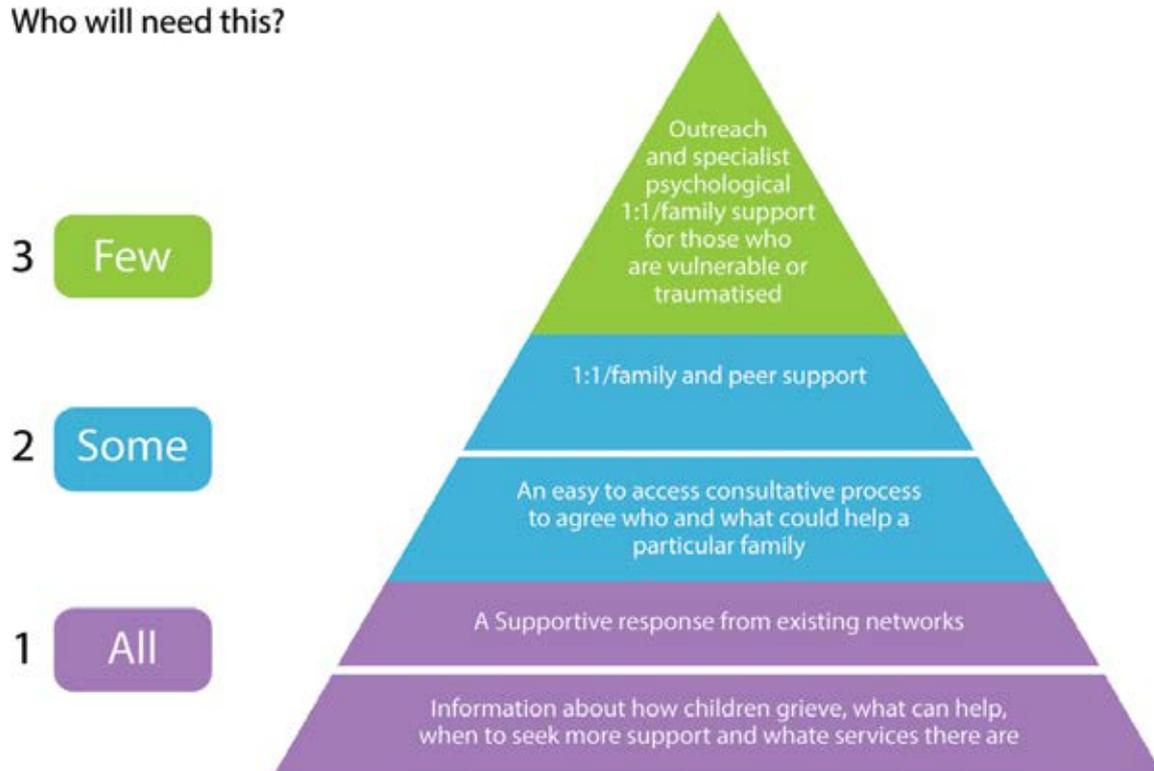


Figure 1: what good local provision for bereaved children and their parents & carers looks like

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.

Monitoring and evaluating provision

Monitoring helps organisations keep track and account of the services provided. Evaluation uses information gathered from monitoring and combines it with other information to judge how well the service is being provided, its impact and value. Services can plan their monitoring and evaluation activity by identifying the key questions they want to answer. These might include

- Number of people using the service, their gender and relationship to the deceased
- Type and duration of service (e.g. group, face to face or telephone contact)
- Source of referrals
- Length of time between bereavement, referral, assessment and the start of an intervention
- The proportion of service users from particular communities
- The difference made to users' outcomes
- Social value and return on investment

Measures suggested for assessment may be used to evidence change before and after taking part in a service, provided the measure has sufficient sensitivity to change. The [Childhood Bereavement Network](#) has a set of common outcome tools being used across childhood bereavement services and the **Bereavement Assessment and Outcomes Task Group** is identifying ways of embedding measures across all-age services.



The policy context for commissioning bereavement services

Responsibility for commissioning bereavement care sits across multiple responsibilities in CCGs, acute trusts and local authorities. After an initial section on the overarching strategies, this section sets out the key policy documents outlining this provision across end of life care, carers' support, maternity services, wellbeing, mental health and suicide prevention.

National Outcome Frameworks and overarching strategies

Bereavement care contributes to the outcomes included in the NHS Outcomes Framework Department of Health (2016a), CCG Improvement and Assessment Framework (NHS England, 2016b), the Public Health Outcomes Framework 2016-19 (Department of Health, 2016) and the Adult Social Care Outcomes Framework (Department of Health, 2014). Appendix 1 details the outcomes that are particularly relevant for bereavement care.

[NHS Five Year Forward View](#) (2014a). Bereavement is a public health issue, and care for bereaved people is closely tied to the following themes:

- Getting serious about prevention
- Support to help people get and stay in employment
- Encouraging people to manage their own health
- Engaging communities in promoting health, supporting carers
- Encouraging community volunteering

Supporting community development approaches to bereavement alongside targeted care is a key way of unleashing the 'renewable energy' of communities described in the Forward View.

[NHS Shared Planning Guidance 16/17-20/21](#) (NHS England & NHS Improvement, 2016) This vision of better health, better patient care and improved NHS efficiency outlines a new approach to help ensure that health and care services are built around the needs of local populations. Each of 44 areas are producing a multi-year Sustainability and Transformation Plan (STP), showing how local services will evolve and become sustainable over the next five years. The planning guidance asks areas to consider how they will deliver patient choice around end of life care.

[NHS Mandate](#) (Department of Health, 2017) sets out objectives to 2020, underpinned by specific plans for 2017/18. The following are relevant to bereaved carers and to bereaved people with mental health difficulties.

- Objective 2: To help create the safest, highest quality health and care service.
2.2 Patient Experience: includes a 2020 goal to significantly improve patient choice in end of life care; with 2017-18 plans to identify metrics to assess quality and choice in end-of-life care, ready for inclusion in the CCG improvement and assessment framework for 2018-19; and to develop an implementation plan with clear milestones and metrics for taking forward the recommendations set out in the Government's response to the end-of-life care Choice Review, in collaboration with partners.
- Objective 6: To improve out of hospital care.
6.3 Mental health, learning disabilities and autism: includes a 2020 goal to implement the Mental Health Five Year Forward View (including the 2017-18 deliverables) and to increase the number of children receiving evidence-based treatment. In 2017-18 this should include work with system partners to deliver the Mental Health Five Year Data Plan, the Mental Health Workforce Strategy, the Future in Mind recommendations, and support Government priorities and commitments to improving mental health for children and young people and prisoners and offenders in the community.

[Commissioning for Quality and Innovation \(CQUINs\) guidance for 2017-19](#) (NHS England, 2016c): is intended to deliver clinical quality improvements and drive transformational change. Providing high quality bereavement care can contribute to goal 1: Improving NHS Staff health and wellbeing and to goal 5: Transitions out of Children and Young People's Mental Health Services.

[The Leading Change, Adding Value](#) (NHS England, 2016d) framework supports nursing, midwifery and care staff in closing the three gaps (health and wellbeing, care and quality, funding and efficiency) by focusing on unwarranted variation in outcomes, experiences, and use of resources. It includes commitments to innovative and targeted prevention work, and partnership with families and carers.

End of Life Care policy

End of life care policy is a crucial area for bereavement care, around expected, unexpected and sudden deaths.

[End of Life Care Commissioning Toolkit](#) (NHS England, 2016e) states that commissioning plans must encompass bereavement and pre-bereavement care, including care for children and young people.

[NHS England Specialist Level Palliative Care: Information for commissioners](#) (NHS England, 2016f) identifies that specialist palliative care includes providing care and support to those important to the person receiving care, including facilitating bereavement care. The sample specification includes the strand 'Identify and assess the needs of those important to the person, including psychological and social needs, and provide support, preparation for the caring role at whatever level is required to be undertaken, and facilitate access and signposting to other services, including pre-bereavement and bereavement.'

[Every Moment Counts](#) (National Voices, 2015) underlines the central importance of bereavement care to achieving a good death. A set of 'I statements' provide a narrative for person-centred, coordinated care near the end of life:

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

"I am confident that the people who are important to me will have the opportunity to get support with bereavement before and after my death."

"Taken together, the information, care and support I receive helps me feel 'at peace' about what will happen in the future, including how the people who are important to me will cope after I die, and be supported to do so."

[End of Life Care Quality Standard](#) (NICE, 2011) covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. This includes adults who die suddenly or after a very brief illness. Quality Standard 7 covers holistic support for families and carers, and Quality Standard 14 covers bereavement support (appendix 2).

The [Ambitions for End of Life Care](#) (National Palliative and End of Life Care Partnership, 2015) state that good end of life care includes bereavement and pre-bereavement care, including for those affected by deaths caused by sudden illness or trauma, including suicide. Support should be provided for bereaved children and young people as well as adults. Although the Ambitions focus on the needs of the dying person, the document states that they should also be read as ambitions for carers, families, those important to the dying person, and where appropriate for people who have been bereaved. The relevant ambitions for people facing and following bereavement are:

Ambition 1: Each person is seen as an individual: Good End of Life Care includes bereavement

Caring for the individual includes understanding the need to support their unique set of relationships with family, friends, carers, other loved ones and their community, including preparing for loss, grief and bereavement.

Ambition 2: Each person gets fair access to care - Community partnerships

Dying, death and bereavement affects everyone, so everyone must be able to get care that works for them personally, for their family and carers and for their communities. Local plans should include the development of community partnerships between different faith groups and cultural communities, as well as the diverse organisations that support children and young adults, people living with different life shortening illnesses, and those managing the difficulties of older age.

Ambition 6: Each community is prepared to help

"I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways."

[Each Community is Prepared to Help](#) (National Council for Palliative Care, 2016) expands the public health approach outlined in ambition 6, setting out ways in which professional organisations can actively participate in helping to build supportive communities.

NICE [Guidance on Improving Supportive and Palliative Care for Adults with Cancer](#) (2004) provides a model for local bereavement support (see appendix 3) and the [End of Life Care Strategy](#) (Department of Health, 2008) subsequently applied this model to bereavement following all expected deaths. This guideline will be retained alongside End of Life Care for Adults in the Last Year of Life: service delivery (NICE, forthcoming 2018). A parallel set of guidance on [End of Life Care for Infants, Children and Young People](#) (NICE, 2016) includes the provision of care and support for parents, carers and families including siblings.

Together for Short Lives' [Perinatal Pathway for Babies with Palliative Care Needs](#) (2017) includes a focus on high quality end of life and bereavement care.

[Priorities for Care of the Dying Person : Once Chance to Get it Right](#) (Leadership Alliance for the Care of Dying People, 2014) describes care in the last days and hours of life. The fourth priority states that 'The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.'

[Response to the Review of Choice in End of Life Care](#) (Department of Health, 2016c) sets out how the government will respond to the review's recommendations that carers should be formally identified and supported in line with the Care Act 2014, and supported following bereavement, and that family members, carers and/or those important to the individual should be involved in discussions about care preferences where the dying person has said they should be.

[The End of Life Care Core Skills Education and Training Framework](#) (Health Education England 2017) sets out the skills needed to deliver high quality care. Section 9 is on support for carers, including into bereavement. The [e-ELCA e-Learning programme](#) enhances education and training for end of life care.

Support for carers

Some people have extensive experience of caring before they are bereaved, and so support for carers is a necessary – though not sufficient¹ – aspect of bereavement care. Pre-bereavement levels of mental distress influence how well a carer will manage after the death. Feeling exhausted and overloaded, lacking support, and having competing responsibilities such as work or caring for younger children are all associated with poor bereavement outcomes (Schulz et al, 2008a).

1. Carers and bereaved people are distinct groups. Most carers will feel themselves to be bereaved when the person dies, but the pool of bereaved people is wider than this. Many bereaved people would not have identified themselves as carers before the death, and nor would they have qualified for a carers' assessment.

Under the **Care Act 2014**, local authorities and health bodies are required to work together to identify carers. Local authorities have responsibility to provide 'care and support functions' to adult and young carers themselves, who have a legal right to assessment and support. These responsibilities are set out in statutory guidance. The Local Government Association produces resources on supporting carers, including [A Guide to Efficient and Effective Interventions for implementing the Care Act as it applies to Carers](#) (2014). This sets out what local authorities can do to fulfil the requirements and expectations of the Act.

[NHS England's Commitment to Carers](#) (2014b) set out 37 high level commitments, including mention of bereaved former carers. The [Commissioning for Carers Principles](#) (NHS England, 2014c) help commissioners identify good practice and plan for improvement in commissioning carers' support.

Support following a death

[When a person dies](#) (National End of Life Care Programme, 2011) identifies good practice in bereavement care around the time of death and shortly afterwards, setting out provision in detail, with a particular focus on acute settings. The National Paediatric Hospitals Bereavement Network is developing standards and guidance for bereavement care following the death of a child in an acute setting.

[National Guidance on Learning from Deaths](#) (National Quality Board, 2017) sets out a framework for NHS Trusts and NHS Foundation Trusts on identifying, reporting, investigating and learning from deaths in care. Chapter two focuses on bereaved families. Providers should have a clear policy for engagement with bereaved families and carers, and should offer a bereavement service for families and carers of people who die under their management and care. NHS England, led by the Chief Nursing Officer, will develop guidance in 2017-18 for bereaved families and carers which will cover how families should be engaged in investigations.

[Working together to safeguard children](#) (Department for Education, 2015) sets out the statutory responsibilities for investigating sudden or unexpected child deaths, including providing support to the bereaved family, involving them in meetings as appropriate, referring to specialist bereavement services where necessary and keeping them up to date with information about the child's death. The Child Death Overview Process is currently (June 2017) under review and NHS England, the Department of Health and Department for Education are expected to issue new statutory guidance.

The Royal College of Pathologists and the Royal College of Paediatrics and Child Health's [Sudden and Unexpected Death in Infancy and Childhood](#) (2016) sets out multi-agency guidance for care and investigation. A key component is ongoing consideration of the psychological and emotional needs of the family, including referral for bereavement support.

Sands is leading a group of baby loss charities to develop a [National Bereavement Care Pathway](#) with a focus on pregnancy loss and the death of a baby.

[Guide to Coroners Service](#) (Ministry of Justice, 2014) gives statutory guidance that the coroner's office will provide information on the main local and national voluntary bodies, support groups and faith groups which help bereaved people, including as a result of particular types of incidents or circumstances, or specific medical conditions.

Support for people bereaved by suicide

[Preventing Suicide in England](#) (HM Government, 2012) is a cross-government outcome strategy including the provision of better information and support to those bereaved or affected by suicide. Specific actions for postvention include providing support that is effective and timely; having in place effective local responses to the aftermath of a suicide; and providing information and support for families, friends and colleagues who are concerned about someone who may be at risk of suicide.

[Support after a suicide: A guide to providing local services](#) (Public Health England, 2017) sets out in detail the commissioning and delivery of suicide postvention support, and is supported by National Suicide Prevention Alliance guidance on [National Suicide Prevention Alliance guidance on Developing and delivering local bereavement support services](#) (2016a) and [Evaluating local suicide bereavement support services](#) (2016b).

Support for people bereaved by homicide

[The Serious and Organised Crime Strategy](#) (HM Government, 2013) sets out support for victims including people bereaved through murder and manslaughter. The [Code of Practice for Victims of Crime](#) (Ministry of Justice, 2015) sets out the services that bereaved families are entitled to receive as victims of the most serious crimes, including the assignment of a Family Liaison Officer, accessible information on bereavement and information on available victim support services and contact with the Crown Prosecution Service.

Support for wellbeing

[Social and emotional wellbeing in the early years](#) (2012), [primary](#) (2008) and [secondary](#) (2009) education set out the National Institute for Clinical Excellence's recommendations for local practice, including pastoral support, curriculum development and training so that staff can discuss difficulties with parents and refer on when necessary, including around bereavement. The [Older people: independence and mental well-being](#) (NICE 2015) guideline covers interventions for people aged 65 or older, and how to identify those most at risk of a decline, including those bereaved of their partner.

Support for people with mental health difficulties

Bereavement is not a mental illness, but it is associated with an increased risk of developing mental health problems. The NHS has published an [implementation plan](#) (2016g) in response to the [Five Year Forward View for Mental Health](#) (Mental Health Taskforce, 2016), setting out objectives for local areas to reach by 2020/21. This follows on from the cross-government mental health outcomes strategy [No Health without Mental Health](#) (HM Government, 2011), which aspires to a vision where more people will have good mental health and better well-being across the life course, and where more people with mental health problems will recover.

[Future in Mind](#) (Children and Young People's Mental Health Taskforce, 2015) sets out aspirations for support for children and young people by 2020, including timely access to clinically effective mental health support, a move away from the tiered model to a system built around children's needs, improved support for parents to help build resilience, a rigorous focus on outcomes, and better training for professionals.

[Guidance on producing a Local Transformation Plan](#) (NHS England, 2015) sets out how CCGs can work in partnership with their Health and Well-being Boards and partners from across the NHS to support improvements in children and young people's mental health and wellbeing.

Emergency preparedness

[Emergency Response and Recovery](#) (Cabinet Office, 2010), describes the multi-agency framework for responding to, and recovering from, civil emergencies in the UK, and includes aspects of support for families bereaved in emergencies. It aims to develop a shared understanding of multi-agency response and recovery arrangements across responding agencies.

Appendix 1: Bereavement in the national frameworks

NHS Outcomes Framework (NHS OF)

(Department of Health, 2016a)

Domain 1: Preventing people from dying prematurely

1.1 - 4	Reducing premature mortality from the major causes of death (under 75)	While overall numbers of bereaved people who die early are low, the death of a spouse is associated with increased risk of death from cardiovascular disease, coronary heart disease, stroke, all cancer, lung cancer, smoking-related cancer, and accidents or violence. The risk may be greater among those bereaved unexpectedly (Hart et al, 2007). Children bereaved of a parent during their childhood are at persistent risk of themselves dying early (Li et al, 2014; Smith et al, 2014). Parents whose baby or young child dies have a markedly increased risk of mortality up to 25 years after their child's death (Harper et al, 2011).
1.5	Reducing premature mortality in people with mental illness	While bereavement itself is not a mental illness, it does increase the risk of a range of mental health difficulties including complex grief reactions, depression, PTSD symptoms and anxiety, and also increases the risk of mortality (Stroebe et al, 2007).

Domain 2: Enhancing quality of life for people with long-term conditions

2.4	Enhancing quality of life for carers	'The most common finding across multiple studies is that pre-bereavement levels of mental distress such as depression and anxiety are predictive of post-bereavement adjustment. A related finding is that high levels of burden, feeling exhausted and overloaded, lack of support, and having competing responsibilities such as work or caring for younger children are all associated with negative post-bereavement outcomes.' (Shulz et al, 2008b).
2.5	Enhancing quality of life for people with mental illness	People experiencing problematic grief including prolonged grief disorder, complicated grief and major bereavement-related depression have reduced quality of life (Zisook and Shear, 2009; Boelen and Prigerson 2007).

Domain 4: Ensuring that people have a positive experience of care

4.6	Improving the experience of care for people at the end of their lives	This objective is measured by bereaved carer's views on the quality of care in the last three months of life, through the annual VOICES survey. Carers' perception of the support they and their cared-for person received at the end of life is related to their level of grief and mental health after the death (Grande and Ewing, 2009).
4.7	Improving experience of healthcare for people with mental illness	Some studies suggest that those most in need of support from health services following a death are less likely to access them (Prigerson et al, 2001).
4.9	Improving people's experience of integrated care	In 2015, less than half of those who wanted to talk about their feelings about their relative's illness or death with someone from a health, social care or bereavement service got to do so (Office of National Statistics, 2016). (13.3% got to talk, 20.3% wanted to talk but didn't get to, 66.3% didn't want to talk).

Clinical Commissioning Group Outcomes Indicator Set (CCG OIS)

(Health and Social Care Information Centre, 2017)

Domain 1: Preventing people from dying prematurely

1.2 - 1.9	Reducing under 75 mortality	See NHS OF 1.1-1.4 (previous page)
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Domain 2: Enhancing quality of life for people with long-term conditions

2.15	Health-related quality of life for carers, aged 18 and above	See NHS OF 2.4 (previous page)
2.16	Health-related quality of life for people with a long term condition	See NHS OF 2.5 (previous page)

Domain 3 – Helping people to recover from episodes of ill health or following injury

3.14	Alcohol-specific hospital admissions	People whose parent died during their childhood are more likely to be hospitalised for drug or alcohol use than their non- bereaved peers (Wilcox et al, 2010), and young people bereaved suddenly of a parent are more likely to have a substance or alcohol abuse disorder (Brent et al, 2009).
3.15	Emergency alcohol-specific readmission to any hospital within 30 days of discharge following an alcohol-specific admission	See 3.14
3.17	Percentage of adults in contact with secondary mental health services in employment	At any time, one in 10 employees are thought to be affected by bereavement (McGuinness, 2009). Sickness absence attributable to bereavement is likely to be under-reported, as it would likely be recorded as anxiety, depression or stress on a statement of fitness for work.

Domain 4 – Ensuring that people have a positive experience of care

4.3	Family and friends test	The VOICES survey asks about the quality of communication between relatives, friends or carers and health care professionals in the last two days of life. In 2015, 74% respondents agreed or strongly agreed that they had a supportive relationship with the health care professionals. 59% of respondents had definitely been given enough support around the time of death, and a further 27% said they had to some extent (Office of National Statistics, 2016).
4.8	atient experience of community mental health services	See NHS OF 4.7 (previous page)
4.9	Bereaved carers' views on the quality of care in the last three months of life	See NHS OF 4.6 (previous page)

Public Health Outcomes Framework (PH OF)

(Department of Health, 2016b)

Domain 1: Improving the wider determinants of health

1.09	Sickness absence	See CCG OIS 3.17 (previous page)
1.18	Social isolation	Many bereaved people report loneliness following the death, from the loss of the relationship with the person who died, from awkwardness with family members and friends and stigma following certain types of death, and the loss of the staff who supported them while caring for the dying person. Some carers' resources may have become so depleted during caregiving that they are unable to rekindle old relationships or make new ones (Burton et al, 2006). The NICE guideline on Older people: independence and mental well-being (NICE, 2015) identifies that older people bereaved of their partner are at increased risk of decline.

Domain 2: Health Improvement

2.08	Emotional well-being of looked after children	Bereaved children are likely to be overrepresented in the public care system, because many of the factors that contribute to a child becoming looked after also contribute to early mortality (drug and alcohol misuse, poor general health, serious mental health difficulties, domestic violence and involvement in crime). Some young people come into care specifically because there is no-one left to care for them after a death in the family (Penny, 2007).
2.10	Self-harm	Bereavement is a common problem preceding deliberate self-harm in older adults (Hawton and Harris, 2006), and young people bereaved of a parent by cancer are twice as likely to self-harm as those who haven't been bereaved (Bylund-Grenklo et al, 2014). Young people bereaved of a parent are more likely to attempt suicide (Jakobsen and Christiansen, 2011).
2.15	Drug and alcohol treatment completion and drug deaths	See CCG OIS 3.14 (previous page)
2.18	Alcohol-related admissions to hospital	See 2.18
2.23	Self-reported wellbeing	The death of a parent in childhood has a persistent, worsening effect on teenagers' emotional and social wellbeing, long after the death (Jones et al, 2013). They have lower self-efficacy and self-esteem (Worden, 1996). Bereaved children have lower life satisfaction, even if they are not showing emotional or behavioural difficulties (Parkes et al, 2014). Bereavement has a significant impact across many domains of adults' self-reported wellbeing (Stroebe et al, 2007).

Public Health Outcomes Framework (PH OF)

(Department of Health, 2016b)

Domain 4: Healthcare public health and preventing premature mortality

4.04	Under 75 mortality rate from cardiovascular diseases	See NHS OF 1.1-1.4
4.09	Excess under 75 mortality rate in adults with serious mental illness	See NHS OF 1.5
4.10	Suicide rate	Bereavement is associated with an increased risk of suicide in the bereaved person (Stroebe et al, 2007), including if the bereavement was itself through suicide (Wilcox et al, 2010; Pitman et al, 2016).
4.13	Health-related quality of life for older people	Many bereaved people experience acute suffering, particularly early in their bereavement, which may disrupt their everyday activities. Studies report an increase in depressive symptoms among older bereaved people and some will experience complicated or persistent grief reactions (Stroebe et al, 2007).

Adult Social Care Outcomes Framework (ASC OF)

(Department of Health, 2014)

Domain 1: Enhancing quality of life for people with care and support needs

1A	Social care-related quality of life	This measure is an average quality of life score based on responses to the Adult Social Care Survey. Relevant questions for bereaved people using social care services include those on social participation, occupation and dignity. See 4.13 and PHOF 1.18.
1F	Proportion of adults in contact with secondary mental health services in paid employment	See NHSOF 2.5
1L	Proportion of people who use services, and their carers, who reported that they had as much social contact as they wanted	See PHOF 1.18

Domain 3: Ensuring that people have a positive experience of care and support

3B	Overall satisfaction of carers with support services	The annual VOICES survey collects bereaved people's views on care at the end of life for people over 18. In 2015, 41.8% people reported this as outstanding or excellent, 48% as fair or good, and 10.2% as poor (rising to 13.3% of those whose relative died in hospital). 54.1% those who cared for the person at home reported not getting enough care and support for their caring role during the last three months (rising to 61.9% of those whose relative died in hospital) (Office of National Statistics, 2016).
3C	The proportion of carers who report that they have been included or consulted in discussion about the person they care about	In 2015, around a quarter of people registering a death didn't get to discuss their worries/fears about the person's condition, treatment or tests with their GP as much as they would have liked in the 3 months prior to the person's death. 76% report being as involved as they wanted to be in decisions around the person's care and 23% wanted to be more involved (this figure was higher among those whose relative died in hospital) (Office of National Statistics, 2016).
3D	The proportion of people who use services and carers who find it easy to find information about services	In 2015, less than half of those who wanted to talk about their feelings about their relative's illness or death with a health, social care or bereavement service got to do so (Office of National Statistics, 2016). One barrier may be knowledge of services.

CCG Improvement and Assessment Framework (CCG IAG)

Better Health

105c	Percentage of deaths which take place in hospital	Some deaths in hospital are desired and/or unavoidable. However, the annual VOICES survey finds that people whose relative died in hospital consistently report the care as less satisfactory than that of those who died at home or in a hospice. In 2015 66% of relatives of those who died in hospital reported supportive relationships with health care professionals in the last two days of life, compared with 79% at home and 91% in a hospice (Office of National Statistics, 2016).
108a	Quality of life of carers	See NHSOF 2.4

Better Care

123c	Children and young people's mental health transformation	Bereavement increases children's risk of a range of mental health difficulties both in childhood and later adulthood (Penny and Stubbs, 2015). Bereaved children are one of the potentially vulnerable groups for whom the National CAMHS Review recommended commissioners should have particular regard (Department for Children Schools and Families and Department of Health, 2008).
128b	Patient experience of GP services	See NHSOF 4.7

Appendix 2: Bereavement in the End of Life Quality Standard 13 (National Institute for Health and Clinical Excellence, 2011)

This NICE quality standard defines clinical best practice within this topic area. It provides specific, concise quality statements, measures and audience descriptors to provide the public, health and social care professionals, commissioners and service providers with definitions of high-quality care.

This quality standard covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. This includes adults who die suddenly or after a very brief illness. The quality standard does not cover condition-specific management and care, clinical management of specific physical symptoms or emergency planning and mass casualty incidents.

Quality statement 7: Holistic support – families and carers

<https://www.nice.org.uk/guidance/QS13/chapter/Quality-statement-7-Holistic-support-families-and-carers>

Quality Statement: *Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.*

Commissioners ensure they commission services that offer comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

Structure	Data source	Process	Data source	Outcome	Data source
Evidence of local arrangements to ensure that families and carers of people approaching the end of life receive comprehensive holistic assessments in response to their changing needs and preferences.	Quality and Outcomes Framework (QOF) indicator MANAGEMENT 9 (primary care): The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment. The Operating Framework for the NHS in England 2011-12 integrated performance measure SQU08: Agree and make available to local people policies, plans and budgets to support carers (not specific to end of life care).	Proportion of nominated informal carers (such as a family member) of people identified as approaching the end of life, who receive a comprehensive and holistic assessment of their own needs and preferences. Numerator – the number of people in the denominator receiving a comprehensive and holistic assessment of their own needs and preferences. Denominator – the number of nominated informal carers (such as a family member) of people identified as approaching the end of life.	Local data collection. Local Authority National indicator 135: Carers receiving needs assessment or review and a specific carer's service, or advice and information (not specific to end of life care). The draft End of life care locality register pilot programme core dataset from the Information Standards Board records carer details. The draft comprehensive dataset records whether there is a care plan in place for the carer.	Carers and families of people approaching the end of life feel supported.	Local data collection. 2011/12 Adult Social Care Outcome Framework indicators 3B – Overall satisfaction of carers with social services and 3C – The proportion of carers who say that they have been included or consulted in discussions about the person they care for (not end of life care specific). Office for National Statistics (ONS) National bereavement survey (VOICES) includes a question on whether the responder and their family got as much help and support from health and social services as they needed when caring for the person who died and whether they were able to discuss any worries and fears they may have had about the person's condition, treatment or tests with GPs.

Structure	Data source	Process	Data source	Outcome	Data source
Evidence of local arrangements to ensure that families and carers of people approaching the end of life are offered holistic support appropriate to their own current needs and preferences.	Local data collection.	Proportion of nominated informal carers (such as a family member) of people identified as approaching the end of life, who receive holistic support in accordance with their most recent assessment. Numerator – the number of people in the denominator receiving holistic support in accordance with their most recent assessment. Denominator – the number of nominated informal carers (such as a family member) of people identified as approaching the end of life, who have received an assessment of their own needs.	Local data collection.	Carer quality of life.	Local data collection. The NHS Outcomes Framework 2011/12 indicator 2.4 – Health-related quality of life for carers (not end of life care specific). 2011/12 Adult Social Care Outcome Framework indicator 1D – Carer-reported quality of life (not end of life care specific).

Definitions

A 'holistic' assessment includes, as a minimum: physical, psychological, social, spiritual, cultural, and where appropriate, environmental considerations. This may relate to needs and preferences as well as associated treatment, care and support.

A comprehensive assessment is likely to be multidisciplinary and may require the input of both health and social care professionals, as well as other appropriate support services. A comprehensive assessment is one that is coordinated effectively in order to avoid duplication.

'Carers' here are defined as informal, unpaid carers or supporters, rather than paid health and social care workers. Sometimes the main carer will be a child, a young person or a person with his or her own disability, and services should be sensitive to the particular issues that this may raise.

The term 'families' is broad and relates to any person who has significant contact with the person approaching the end of life, including children, a partner or close friends. Occasionally, particularly in hostels, for example, staff working directly with the person approaching the end of life may fulfil this role.

A carer's assessment is defined by the Department of Health's End of life care strategy: quality markers and measures for end of life care. Carers can be identified for this assessment by social services, GPs and through self-referral by carers themselves.

Support for families and carers may include emotional and psychological support. Training on practical issues should be available for those caring for people approaching the end of life who require extra help with daily living or extensive care. Addressing the needs of carers should also include access to good quality respite care, appropriate to their circumstances. This may include residential and day respite, as well as overnight one-to-one care in the person's home, for example. Support may also encompass planning for other circumstances, for example when carers are taken ill.

The emphasis here is on support being offered to carers. The right of carers to refuse support must be respected. Carers who decline support initially should be offered the opportunity to change their minds later on, if they wish.

Quality statement 14: Care after death – bereavement support

Quality Statement: *People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.*

Commissioners ensure they commission services for people closely affected by a death that include sensitive communication and provision for immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

Structure	Data source for structure	Outcome	Data source for outcome
<p>Evidence of a local needs assessment for bereavement services, detailing specialist support needs for all sections of the community including vulnerable groups such as children and those with learning difficulties.</p>	<p>Local data collection</p>	<p>People closely affected by a death feel that information and support was available to them around the time of death and afterwards, which was appropriate for them and offered at the right time.</p>	<p>Local data collection. Office for National Statistics (ONS) National bereavement survey (VOICES) includes questions on whether enough help and support was provided by the healthcare team to the family or carer at the actual time of death, whether staff dealt with them in a sensitive manner, and whether they have since talked to anyone from health and social services or from a bereavement service, about their feelings about the person's illness and death.</p>
<p>Evidence that a local service specification for bereavement services has been developed in partnership with acute, community, voluntary and private sector providers and local authorities, which includes the provision of specialist support for groups identified in the needs assessment.</p>	<p>Local data collection</p>		

Definitions

People closely affected by a death may include care home residents, staff and volunteers, staff from a variety of health and social care organisations, as well as family members and carers, including children. Children may need particular tailored support.

Families and carers of people who have died suddenly or in an unexpected way, as well as those who were expecting the death, should have access to information and support appropriate to their circumstances.

Draft Spiritual support and bereavement care quality marker 2 on bereavement support recommends that bereaved people are offered support at the time of death that is culturally and spiritually appropriate, immediate, and available shortly afterwards.

Bereavement support may not be limited to immediately after death, but may be required on a longer-term basis and, in some cases, may begin before death.

A stepped approach to emotional and bereavement support may be appropriate, which could include but is not limited to:

- Information about local support services
- Practical support such as advice on arranging a funeral, information on who to inform of a death, help with contacting other family members and information on what to do with equipment and medication
- General emotional and bereavement support, such as supportive conversations with generalist health and social care workers or support from the voluntary, community and faith sectors
- Referral to more specialist support from trained bereavement counsellors or mental health workers

A model of bereavement support is detailed in NICE cancer service guidance recommendation 12.30. Further guidance on bereavement support is available from **When a patient dies: guidance for professionals on developing bereavement services** (Department of Health 2005) and **UK Standards for Bereavement Care** (London Bereavement Network 2001)².

People closely affected by a death should be able to access all support within an appropriate physical environment that facilitates sensitive communication.

Further details on auditing bereavement support are available from draft Spiritual support and bereavement care quality markers and measures for end of life care (NHS National End of Life Care Programme 2011).

2. The documents referred to here have since been updated: [When a Person Dies](#) (National End of Life Care Programme, 2011) and [Bereavement Care Service Standards](#) (Bereavement Services Association and Cruse Bereavement Care, 2014).

Appendix 3: The three-component model of bereavement support

Extract from Chapter 12 of Improving Supportive and Palliative Care for Adults with Cancer (National Institute for Clinical Excellence, 2004, p160)

12.30 A three-component model of bereavement support should be developed and implemented in each Cancer Network to ensure that people's individual needs are addressed through variety in service provision. Cancer Networks should take account of the standards for bereavement care developed by the National Bereavement Consortium. The components should be flexible and accessible when needed around the time of bereavement.

Component 1

Grief is normal after bereavement and most people manage without professional intervention. Many people, however, lack understanding of grief after immediate bereavement. All bereaved people should be offered information about the experience of bereavement and how to access other forms of support. Family and friends will provide much of this support, with information being supplied by health and social care professionals providing day-to-day care to families.

Component 2

Some people may require a more formal opportunity to review and reflect on their loss experience, but this does not necessarily have to involve professionals. Volunteer bereavement support workers/befrienders, self-help groups, faith groups and community groups will provide much of the support at this level. Those working in Component 2 must establish a process to ensure that when cases involving more complex needs emerge, referral is made to appropriate health and social care professionals with the ability to deliver.

Component 3

A minority of people will require specialist interventions. This will involve mental health services, psychological support services, specialist counselling/psychotherapy services, specialist palliative care services and general bereavement services, and will include provision for meeting the specialist needs of bereaved children and young people (being developed as part of the National Service Framework on children and not covered here).

12.31 Provider organisations should be equipped to offer the first component of bereavement support and have strategies in place to access the other components. Services should be accessible from all settings.

12.32 Within the context of family and social support assessments, health and social care professionals involved in delivering care in the terminal phase of illness should assess individual and family coping ability, stress levels, available support and actual and potential needs with respect to the anticipated or actual bereavement.

12.33 Cancer Network-wide protocols should be developed to inform the level of bereavement support offered and the need for follow up and specialist referral, particularly for those at risk of complicated grief reactions. They should apply wherever the patient dies – at home, in hospital, hospice or care home – and should include a system to engage proactively with those assessed to be at risk, involving, for example, follow-up telephone calls or letters to individuals around eight weeks after death. Issues of consent and data protection should be considered carefully.

12.34 Providers should ensure that a leaflet is made available to families and carers around the time of the bereavement. Ideally, this should be developed locally, agreed by those involved in the provision of bereavement services, and include information on anticipated feelings and how to access local and national services.

Appendix 4: Bereavement Care Service Standards

(Bereavement Services Association and Cruse Bereavement Care, 2014)

Fundamental Principles

The following fundamental principles should be integral to any bereavement service that meets the minimum standard:

Confidentiality: services should respect the confidentiality and privacy of each bereaved person and any information shared by them, with due regard to safeguarding, consent and data protection.

Respect: services should respect the individuality of each bereaved person's grief and needs, with each person treated with compassion and sensitivity.

Equality and Diversity: services should be nondiscriminatory and delivered without prejudice, recognising and responding to personal beliefs and individual situations including (but not exclusive to) age, culture, disability, gender, sexuality, race, religion and spirituality (Equality Act 2010).

Quality: services should ensure that all those delivering support to bereaved people, whether in a paid or voluntary capacity, have the skills, knowledge, training, supervision and support relevant to their role, and that services work to improve what they offer.

Safety: services should have robust processes for recruitment, including appropriate levels of clearance with the Disclosure and Barring Service and ongoing staff/volunteer development. There needs to be due regard to safe and ethical practice in order to protect bereaved people and those who work with them. The necessary processes for safeguarding must be in place and accountability evidenced through an audit trail.

Service Standards

Assessment: Bereaved people have their needs assessed in a manner appropriate to the service offered. This will be a continuous and ongoing two-way process that ensures both risk and potential for resilience are identified. An appropriate plan is put in place to meet the identified needs of the bereaved person.

1. Service staff/volunteers assess presenting situation and formulate plan of action
2. Service staff/volunteers undertake regular review of progress with the bereaved person with appropriate action taken
3. Service staff/volunteers use an assessment tool/ framework and document accordingly

Support and Supervision: Services provide access to support and supervision to ensure safe working practice and afford staff and volunteers the opportunity to recognize the impact of this work on them.

1. Service staff/volunteers have ready access to timely ad hoc support
2. Staff/volunteers have access to and attend regular structured support activities
3. Service staff/volunteers have access to regular supervision as a requirement of continued practice

Planning: Services have plans in place to address the needs of the client group/ community they serve in the most appropriate way

1. Service is planned in response to identified need
2. Service regularly reviews plans and evaluates activity to ensure development in line with emerging needs
3. Service has awareness of/participates in relevant research initiatives to ensure support constitutes evidence-based practice

Awareness and Access: Services facilitate individual choice; are clear about what they can offer and to whom; know their limitations within defined boundaries and are able to signpost as appropriate.

1. Clear information is available in a user-friendly form about the service and what it can offer, and about other local or national bereavement services, agencies and support resources, for signposting or onward referral purposes
2. Service offers immediate response, whether by telephone, online or in person, and sets out acceptable waiting times and operates within them
3. Service works collaboratively with other statutory, community, commercial, voluntary or faith sector services to meet the diverse needs of bereaved people and maximise the potential for access to appropriate services

Education and Training: All staff and volunteers who come into contact with bereaved people have the necessary skills and knowledge to provide support to these people.

1. Staff/volunteers receive general education about communication skills and bereavement awareness
2. Staff/volunteers receive specialised training pertinent to their area of work
3. Staff/volunteers receive opportunities to access externally accredited training and development opportunities to ensure continued good practice

Resources: Resources are allocated so they are responsive to the differing needs of bereaved people.

1. Service provides designated areas and resources for providing bereavement care
2. Service provides access to communication support, e.g. interpreters
3. Service provides appropriate ratios of staff/volunteers to bereaved people, especially in relation to vulnerable and young people

Monitoring and Evaluation: Services continually review the support offered to ensure they are meeting the needs of bereaved people and to inform developments in the service.

1. Service collects and analyses data, including service user feedback and complaints. Such data is used to improve the quality of the service offered.
2. Service monitors and regularly evaluates performance against the minimum standards and documents accordingly. Such documentation is made available on request to the public. Such data is used to improve the quality of the service offered.
3. Service performance monitored against these minimum standards by independent review/ evaluation. Such reports are made available on request.

Appendix 5: Checklist for Good Practice in Child Bereavement Services

The Childhood Bereavement Network has produced a checklist for good practice in services supporting bereaved children and young people. This is supported by a self-audit tool - [Running A Service](#).

Safe practice

How do you ensure that:

- You consider the safety implications for service users and staff across the whole range of your work, for example, individual and group work, transport by volunteers, home visits and email support?
- There is a documented policy to ensure the overall safety of children using your services?
- The policy incorporates a set procedure for the recruitment of paid staff and volunteers?
- All paid and voluntary staff receive training and supervision to ensure the overall safety of children using your service?
- You work within the legislative framework and guidance?
- There is a documented health and safety policy?
- The service is properly insured?
- There is a documented policy on confidentiality which is discussed and agreed with all your service users and staff?

Fair practice

How do you ensure that:

- There is a documented and proactive equal opportunities policy?
- You regularly review your service to identify and change discriminatory practice?
- You regularly undertake a needs assessment to review the accessibility and appropriateness of your service?
- You are able to respond to the needs of bereaved minority ethnic children, young people and their families?
- You are able to respond to the needs of bereaved disabled children, young people and their families?

Sustainable practice

How do you ensure that:

- You regularly undertake a needs assessment to review the appropriateness of your work or service?
- You liaise with users, key referral agencies, staff and other professionals working in your catchment area regarding any proposed service development?
- Your service is appropriately resourced, with good access to a safe space, room or premises and a budget to buy equipment?
- There is a business plan, including a funding strategy to ensure the sustainability of your service?
- The principles embodied in the Childhood Bereavement Network Belief Statement are incorporated into your practice and the service you provide?
- You have a statement of values and principles or mission statement with clear aims to define the remit of your service?
- There is a written definition of your service that clearly sets out details of the information, guidance and support you offer and is regularly reviewed and updated?
- This information is circulated to key referral agencies and potential users? You publish and circulate an annual report to key referral agencies and users?
- You liaise with other organisations to raise awareness of the needs of bereaved children, their families and other caregivers?
- You have a procedure to ensure effective liaison with other local, regional or national organisations offering similar services?

Reflective practice

How do you ensure that:

- There is a documented policy to ensure that all staff are appropriately trained to work with bereaved children, their families and other caregivers?
- That training needs are regularly reviewed and all staff are offered regular opportunities to update their skills; and there is a training budget?
- There is a documented policy on supervision; all staff are appropriately supervised and consulted on a regular basis about their supervision needs; and there is a budget for supervision?
- You have procedures to enable you to monitor, evaluate and review the services you provide on a regular basis?
- You encourage feedback on your service from children, young people and their families, staff, key referral agencies and professionals?
- There is a documented and accessible complaints procedure for children, young people, their families, key referral agencies, staff and the public?

Developing policies and procedures

How do you ensure that:

- You have enough resources to develop, monitor and review policies?
- You have a regular, rolling programme to review policies and ensure they comply with legal requirements?
- You involve staff and service users in the process?
- A named staff member or trustee takes responsibility for the process?
- All employees and volunteers are introduced to the policies as part of their induction?
- Ongoing training is provided to help staff develop skills and confidence in using the policies?
- The policies are easy to find, use and monitor?
- The policies cover all aspects of service delivery including face-to-face individual and group work, telephone and email support and web-based activity?

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