Guidelines for Bereavement Support

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Summary of Main Recommendations

BEREAVEMENT SUPPORT
Grief is the normal, emotional response associated with loss. The majority of people who have been bereaved get their support from family and friends and do not need formal bereavement support services.

For some, grief can be associated with significant anxiety and depression. Early identification of individuals who may develop this is important so that more formal bereavement support services can be arranged.

The whole of society, including all health care practitioners, have a role to play in bereavement support before, during and after death.

CARE BEFORE DEATH
Effective communication skills, continuity of care, high quality care and holistic needs assessment which the ‘bridging of life and death’ contributes to effective support. Care before death should include a allows identification of people who may be vulnerable and need more support.

Bereavement assessment tools are recommended for use only as a part of the assessment process. This assessment should include a considered holistic needs assessment by a multidisciplinary team.

CARE AFTER DEATH
UNIVERSAL SUPPORT
NICE Component 1
1
All bereaved people should receive compassionate care which includes an information booklet covering:
- information regarding the emotional impact of bereavement
- coping strategies
- practical information about what happens after someone dies (e.g. Department for Works and Pensions booklet)
- how to access local and national bereavement services

This is additional support provided by peer groups e.g.:
- bereavement support volunteers
- self help groups
- faith groups
- community groups

Bereaved people may self-refer or approach any health professional for guidance.
If support identified prior to death, offers of support should be made 8 to 12 weeks after bereavement

INDICATIVE SUPPORT
NICE Component 3
3
This is additional support provided by accredited professionals e.g.:
- general bereavement services
- specialist palliative care bereavement services
- psychological support services
- mental health services

Bereaved people may self-refer or approach any health professional for guidance. Health professionals should be aware of available local services

Further resources to support this guideline can be found on our website:

Cheshire & Merseyside Palliative & End of Life Care Strategic Clinical Network Standards & Guidelines

NICE has accredited the process used by the Cheshire and Merseyside Palliative and End of Life Care Network Audit Group to produce Palliative care and end of life care guidelines. Accreditation is valid for 5 years from 10 January 2017 and is retrospectively applicable to guidance produced using the processes described in the Cheshire and Merseyside Palliative and End of Life Care Network Audit Group guideline development manual (2016).
For full details on our accreditation visit: www.nice.org.uk/accreditation
Guidelines for Bereavement Support

Date of Production: November 2017
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Cheshire & Merseyside Palliative & End of Life Care Strategic Clinical Network
Standards & Guidelines

Bereavement Care Algorithm

Universal & Public Health Care
Communities, General & SPC Services participate in societal engagement in death, dying & bereavement e.g. Dying Matters, Compassionate Communities, Information or education sessions on bereavement, Memorial services

Holistic Needs Assessment for the person with life-limiting illness & those important to them known including checked, up-to-date contact details

Effective, sensitive communication
Pre-bereavement need identified? ➔ Support given

Death Occurs

General Palliative Care & Clinical Team
(e.g. District Nurse, General Practitioner, Care Home, Ward Staff, Hospital Bereavement Office)

Provides Component 1 support:
- contact made with those important to the dying person within 48 hours of death
- leaflet includes emotional impact of grief and coping strategies, practical information of what to do after death & local support services contact details

Specialist Palliative Care Team

SPC services offering Component 1 support:
- Engages with local services to ensure Component 1 care meets standards

Objection to contact
No objection to contact

Discharge

Letter sent at 8 - 12 weeks offering follow up
Await response

Assessment

Self-referral to GP, DN, SPC for help in bereavement

Component 1 Universal Support
Telephone Contact
Literature about grief

Component 2* Selective Support
Volunteer Support
Peer Support

Component 3* Indicative Support
Bereavement Support Worker
Bereavement counselling
Clinical Psychology
Mental Health Services/ Psychiatry

NICE Component 1 Interventions
NICE Component 2 Interventions
NICE Component 3 Interventions

* Components can be delivered by Specialist Palliative Care Services or by onward referral to other organisations

Key

Bereavement Care Algorithm

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Section 1: Introduction

- **Bereavement** is the state of loss resulting from death.¹
- **Anticipatory grief** is the emotion felt prior to an expected death.¹,²
- **Grief** is the normal, emotional response associated with loss and can include other life events apart from death. The focus in this guideline is on grief relating to death. Grief is multi-dimensional and diverse in its expression. Grief has psychological, emotional, physical, spiritual, economic, behavioural and social dimensions. The expression of grief and mourning is influenced by culture and ethnicity.¹,²
- The majority of people who have been bereaved get their support from family and friends and do not need formal bereavement support services.³-⁶
- Although grief is normal, for some it may be more challenging and be associated with significant anxiety and depression.⁵,⁶ Early identification of individuals who may develop this is important.⁷
- Bereavement is associated:
  - For a minority with excess risk of mortality (e.g. through higher risk behaviours like smoking)⁸,⁹
  - For a significant minority with increased use of health services⁹
  - For a significant minority with subsequent worse mental and physical health.⁸,¹⁰

  If the latter persists then grief may become complicated or prolonged⁹,¹⁰
- Providing information about grief and how to access help promotes resilience.¹¹
- Complicated grief occurs when grief develops into a debilitating, functional impairment from psychological, social, or physical morbidity.¹ As a concept complicated grief has undergone a number of changes and developments over the years from ‘traumatic grief’ to complicated grief disorder’ and ‘prolonged grief disorder’.¹²
- Appendix 1 shows the diagnostic criteria of **Prolonged Grief Disorder (PGD)** and **Persistent Complex Bereavement Disorder (PCBD)**, formerly known as complicated grief.

- A systematic review identified that 10% - 20% of bereaved people may develop PCBD / PGD.¹² Many more people may experience great distress over a lengthy period and over 33% will have symptoms of anxiety and depression.¹⁰ Bereavement support may assist in resilience and is not only required for people with prolonged grief disorder.¹¹
- **Disenfranchised grief** is the hidden loss of individuals from marginalised or minority groups where there is less social permission to express loss.¹ Groups that may have disenfranchised grief include – but are not limited to – those in care homes, those with a learning disability, black and minority ethnic groups and those identifying as LGBTQI (lesbian, gay, bisexual, transgender, queer or intersex).¹²-¹⁶
The whole of society, including all health care practitioners, has a role to play in bereavement support before, during and after death. These, and other organisations include the following:17

Section 2: Scope and Purpose

- The following guideline is an update of Guidelines for Bereavement Services in Palliative Care developed in 2003 and updated in 2006 and 2009.18
- This guideline is for healthcare, allied and social care professionals and volunteers to support people who have been bereaved.
- It is also a source of information for people with a life-limiting illness, the bereaved and those important to them.
- Table 1 summarises the scope and purpose of this guideline.

Table 1: Scope of guideline

<table>
<thead>
<tr>
<th>Bereavement officers within acute care</th>
<th>Chaplaincy</th>
<th>Primary Healthcare Teams</th>
<th>Specialist Palliative Care Teams</th>
<th>Out of Hours services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambulance Service</td>
<td>Social Services</td>
<td>Police</td>
<td>Mental Health services</td>
<td>Registrar Officers</td>
</tr>
<tr>
<td>Funeral Directors</td>
<td>Care Homes</td>
<td>Drug and Alcohol Agencies</td>
<td>Voluntary organisations e.g. Cruse, Samaritans</td>
<td>Prisons</td>
</tr>
<tr>
<td>Schools and Universities</td>
<td>Compassionate Communities</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Section 3: Methods

- The guideline is based on the AGREE II criteria which may be found in detail in the Cheshire and Merseyside Palliative and End of Life Care Network Audit Group (CMPCNAG) Guideline Development Manual.19

## 3.1 Clinical Questions & Interventions

- Clinical questions were derived from the previous guidance published in 2003 and reviewed in 2006 and 2009. The questions were initially framed by delegates attending the CMPCNAG Review meeting on 12th March 2015 and refined at a meeting of the Guideline Development Group on 13th May 2015. The clinical question used to guide the literature review in PICO (Patient, Intervention, Control, and Outcome) format is:
  - “What is the effectiveness [Outcome] of bereavement services [Intervention] in supporting those important to people with life-limiting illnesses cared for by specialist palliative care services [Population]?”

## 3.1.1 Outcomes

- To provide effective and timely care for people who have been bereaved through:
  - Improved knowledge of bereavement as a life event
  - Aiding education and training to develop skills and behaviours in health and social care professionals. e.g.
    - Supporting people with life-limiting illness and those important to them with loss that occurs before, at the point and after death
    - Recognising people that may be in need of greater support before and after death and who may be at risk of complicated grief or prolonged grief disorder
  - Guiding service development in bereavement care
3.2 Literature Search

- Systematic electronic database searches were conducted to find potentially relevant articles. PubMED, EMBASE (Scopus), CINAHL and Cochrane databases were searched in October 2015. A full explanation of the search strategy, results and appraisal of evidence may be found on the Cheshire and Merseyside Palliative and End of Life Care Network Audit Group website. Grading of level of evidence and recommendations follows the Cheshire and Merseyside Palliative and End of Life Care Network Audit Group Guideline Development Manual and uses SIGN criteria.¹⁹

Section 4 Guideline Recommendations

✓ Indicates a good practice recommendation

4.1 Care before Death

- Bereavement experiences may be affected by the quality of care received by the dying person and those important to them during the dying phase.²⁰-²² Irrespective of where the dying person is being cared for, effective communication skills, continuity of care and the ‘bridging of life and death’ contributes to effective support for the dying person and those important to them before and after death in what can be a frightening time.²³-²⁵ Care before death should move as seamlessly as possible into bereavement support. [Level 2-]

- The opinion of the bereaved in improving care for people with life-limiting illness is important and may have a therapeutic effect.²⁶ All health care services should review the results of the annual VOICES survey and consider using a validated tool such as the Care of the Dying Evaluation (CODE) to better understand end of life care and care of the dying in their service.²⁷,²⁸ [Level 2]

4.1.1 Assessing Bereavement Need

- Care before death should include a holistic needs assessment which allows identification of people who may need more support in bereavement.²⁹ To carry out the most effective holistic pre-bereavement assessment, the assessor should be able to use advanced communication skills, and knowledge of the risk factors. They also need appropriate time to work with the family members and patients.²⁹ [Level 2-]

- Bereavement risk assessment tools may be useful in identifying the social and psychological dimensions of care in those facing bereavement.²⁹ However their sensitivity and specificity to predict who will benefit most from bereavement service interventions in palliative care populations is unproven.²⁹ Over-reliance on these tools risks an overly formulaic approach to assessment.²⁹ Bereavement assessment tools are recommended for use only as a part of an assessment process. A patient review should include a considered holistic needs assessment by a multidisciplinary team. [Level 2++]

- Table 2 summarises factors that may predispose to a poor bereavement outcome; the key overarching factor is vulnerability
### Table 2: Factors associated with Complex Grief \[^5,9,12,30-32\text{[Level 2 ++]}\]

| Demographics                        | • Limited social network  
|                                   | • Multiple bereavements  
| Mode of death                      | • Distressing illness and/or death  
| Health status of the bereaved      | • Prior history of mental illness  
| Psychological preferences or traits of the bereaved | • Coping style and personality  
|                                   | • Relationships with a high need for dependency  
|                                   | • Learned fear and learned helplessness  
|                                   | • Negative construction of the meaning of events e.g. “glass half empty”  

#### 4.2. Care at and after Death

- Regardless of diagnosis or relationship to the bereaved, bereavement support should follow the NICE Improving Supportive and Palliative Care for Adults with Cancer three-component model.\[^2\text{[Level 1-]}\]
- Table 3 summarises the guidance and provides examples of interventions for each component in the model.
<table>
<thead>
<tr>
<th>Component</th>
<th>Description</th>
<th>Examples of Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Universal</td>
<td>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 grief support, with information being supplied by health and social care professionals providing day-to-day care to families.</td>
<td>Bereavement information leaflets Literature – adult grief Literature – children’s grief Telephone support to acknowledge death Sympathy cards or letters to acknowledge death Information/education sessions on bereavement Memorial services</td>
</tr>
<tr>
<td>2. Selective</td>
<td>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 interventions.</td>
<td>Telephone support One-to-one support Home visits Referral to support groups run by other agencies Provide support group Provide one-to-one volunteer support Referral to one-to-one volunteer support provided by an external agency</td>
</tr>
<tr>
<td>3. Indicative</td>
<td>A minority of people will require specialist interventions. This will involve mental health services, psychological support services, specialist palliative care services and general bereavement services, and will include provision for meeting the specialist needs of bereaved children and young people.</td>
<td>One-to-one support by formally trained bereavement support worker Home visits by formally trained bereavement support worker Bereavement counselling Clinical Psychology Mental Health Services / Psychiatry</td>
</tr>
</tbody>
</table>

Figure 1 summarises the NICE guidance as a suggested model of bereavement care.
Universal & Public Health Care

Communities, General & SPC Services participate in societal engagement in death, dying & bereavement
E.g. Dying Matters, Compassionate Communities, Information or education sessions on bereavement, Memorial services

Holistic Needs Assessment for the person with life-limiting illness & those important to them known including checked, up-to-date contact details

Effective, sensitive communication
Pre-bereavement need identified? → Support given

Death Occurs

General Palliative Care & Clinical Team
(e.g. District Nurse, General Practitioner, Care Home, Ward Staff, Hospital Bereavement Office)
Provides Component 1 support:
- contact made with those important to the dying person within 48 hours of death
- leaflet includes emotional impact of grief and coping strategies, practical information of what to do after death & local support services contact details

Specialist Palliative Care Team
SPC services offering Component 1 support:
- Engages with local services to ensure Component 1 care meets standards

Objection to contact
No objection to contact

Discharge
Letter sent at 8 - 12 weeks offering follow up
Await response

Self-referral to GP, DN, SPC for help in bereavement

Assessment

DECLINED or NO RESPONSE

Component 1
Universal Support
Telephone Contact
Literature about grief

Component 2*
Selective Support
Volunteer Support
Peer Support

Component 3*
Indicative Support
Bereavement Support Worker
Bereavement counselling
Clinical Psychology
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NICE Component 1 Interventions
NICE Component 2 Interventions
NICE Component 3 Interventions

* Components can be delivered by Specialist Palliative Care Services themselves or by onward referral to other organisations

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4.2.1 Component 1 – Universal Support

- In bereavement, people express the need for:
  - information to help them decide whether they need to use a bereavement service [Level 2+]
  - a preference for support from services involved in the care of the person who died providing bereavement support after death (e.g. GPs, District Nurses, Specialist Palliative Care Services) [Level 2+]
- The initial contact regarding bereavement support should be made by the clinical team involved in caring for the dying person. [Level 1]
- All provider organisations should be equipped to offer Component 1 of bereavement support and should have access to the other components within their Clinical Commissioning Group and Specialist Palliative Care Service Group.
- All bereaved people, regardless of where the bereavement occurs, should receive an information booklet about bereavement and the services that are available including:
  - information regarding emotional impact of bereavement
  - coping strategies
  - practical information about what happens after someone dies (e.g. Department for Work and Pensions leaflet 34)
  - self-referral and how to access local and national services [Level 1]
- A record of information distributed should be retained for audit purposes and kept in the clinical record.

4.2.2 Component 2 – Selective Support

- There is strong evidence that the universal use of intensive bereavement interventions does not alter bereavement outcomes; therefore Component 2 and 3 interventions should be targeted at those most in need. [Level 1]
- The strongest evidence is for targeted and specific intervention for people with more complex grief reactions. [Level 1]
- There is strong evidence to show that motivation on the part of the bereaved is required for bereavement care interventions to be effective. Consent should be obtained prior to commencing the intervention. [Level 1]
- When the family or the social network of the person who has died is well-known to palliative care services, the need for selective or indicative bereavement support may be assessed by looking at associated risk factors and the multidisciplinary team’s knowledge of the family pre-bereavement as outlined in Section 4.1.1. [Level 2++]
- In services providing Component 2 or 3 care, written contact regarding bereavement support should be made eight to twelve weeks after the death, unless the person/s important to the deceased has clearly stated that they do not wish to be contacted. [Level 4]
Following consent to participate in bereavement support, the bereavement support co-ordinator or delegated professional should work with the bereaved person to determine the Component needed:

- Component 1: no further formal support needs identified [✓]
- Component 2: referral to a service with peer or volunteer support [✓]
- Component 3: referral to a service with a formally trained bereavement service worker, counselling, clinical psychology or mental health/psychiatric support [✓]

If the Specialist Palliative Care Service does not provide a bereavement service in Component 2 or 3, the bereaved person should be referred on to the relevant bereavement service. [Level 4]

The service should be responsive to age, cultural, religious, disability and gender issues affecting bereavement; dealing with them in a sensitive and inclusive way. The service should utilise advocacy and interpreting services appropriate to the type of bereavement care. [Level 4]

Each service should use a systematic assessment process geared to the organisation within which it is located. It should be possible to identify documentation within the clinical record to support audit and quality improvement and may include:

- A risk assessment tool e.g. ‘Responses to Loss’ matrix or equivalent [Level 4]
- Practical information, e.g. whether information leaflets have been given, who completed the form, etc. [Level 4]
- A confidential working agreement (individual support) or an information sheet (group support) [Level 4]
- A written assessment of needs and action plan/outcome measures agreed with client [Level 4]
- A written record of contact [Level 4]
- An on-going review of action plan/intervention [Level 4]

Each service will vary in the process of assessment and the practicalities of service delivery, but when designing an assessment form, consideration should be given to data protection issues such as confidentiality. [Level 4]

When referral on to Component 3 services is indicated, the client must be consulted, fully informed and next steps agreed with them. [Level 4]

There should be a clear process for discharge from the service. Criteria may include:

- Individuals have developed or are developing coping strategies [Level 4]
- Individuals feel they no longer require support from the service [Level 4]
- Symptom(s) associated with complex grief are improving [Level 4]
- Referral on to more appropriate services [Level 4]
4.2.3 Component 3 – Indicative Support

- Specialist palliative care services that offer Component 3 support through counselling or psychology should ensure that services meet the guidelines in Component 2 regarding process and consent.²,¹⁷ [Level 4]
- Any individual who discloses active suicidal intent or behaviours must be immediately referred to their GP or local Mental Health Services with their knowledge. A written record of action should be maintained.²,¹⁷ [Level 4]
- Individuals who require specialist interventions such as mental health services, psychological support services, or specialist counselling/psychotherapy services, should be offered a referral to their GP or given information on other appropriate service providers. A record of action and consent must be documented in the individual's records.²,¹⁷ [Level 4]

4.2.4 Bereavement Support Organisation and Management

- Clinical teams providing bereavement support should clearly outline the remit of the services they provide.²,⁷,¹⁷ [Level 4]
- Specialist palliative care professionals should receive specific training regarding bereavement theory and assessment to allow them to provide Component 1 support and determine appropriate referral for Component 2 and 3 support.²,⁷,¹⁷,³⁹ [Level 4]
- Volunteers involved in Component 2 bereavement support should receive induction and refresher training about bereavement to ensure they provide an effective service.²,⁷,¹⁷ [Level 4]
- Professionals involved in Component 2 and 3 bereavement support should receive adequate training about bereavement (i.e. accredited courses) to ensure effective service provision.²,⁷,¹⁷ [Level 4]
- Volunteers and professionals involved in Component 2 and 3 bereavement support should participate in monthly supervision.²,⁷,¹⁷ [Level 4]
- Bereavement services should obtain feedback from service users e.g. through questionnaires and monitoring complaints.¹⁷ [Level 4]
- Appendix 2 summarises the types of palliative care bereavement services evaluated in the literature.
- Figure 3 summarises the network specification for palliative care bereavement services in NHS Acute Hospital Trusts.

4.3 Public Health Approach to Bereavement

- A minority of bereaved people are proactively offered bereavement services. The majority of bereaved people that are given information about bereavement services choose not to use them. Friends and family provide nearly all bereavement support and GPs provide the majority of professional contact with bereaved people.¹⁴,⁴⁰ [Level 1-]
- The role of friends, family and work colleagues is crucial in supporting bereaved people. Surveys of bereaved people have highlighted improved communication.
skills and sensitivity from friends, family and work colleagues as the biggest help in their grief.⁴¹ [Level 3]

- The End of Life Care Strategy and Ambitions for Palliative and End of Life Care emphasises the importance of societal engagement, an example of which is the work of Compassionate Communities.⁴²-⁴⁴ [Level 2]
- Specialist Palliative Care Services should actively engage in public health work within their communities.⁴³,⁴²-⁴⁴ [Level 2]
- Figure 2 summarises communication strategies to help support bereaved people.
Do it your way. We are all different, and we react to death in different ways. There is no right or wrong way to grieve. Just try to do what feels right for you.

Grief is normal – it is part of what it is to be human and to have feelings.

Grief is a journey – it is often hard, but it will ebb and flow.

Grief has no shortcuts – grief takes time. It often takes much longer than you and many people around you may expect.

It is normal both to grieve and live – when you find yourself not thinking about the person who has died, that is all right.

Allowing your feelings to come out can help you cope with your loss.

Sadness is a natural response to bereavement, but for some people that healthy reaction may become depression. This can be managed and you should see your doctor for help and advice. Your doctor is there to help you. You don’t have to try to cope on your own.

Be kind to yourself – don’t try to do too much while you’re grieving.
## Figure 2: Cheshire and Merseyside Palliative and End of Life Care Strategic Clinical Network – Transform Group: Bereavement Acute Hospitals Specification [Level 4]

<table>
<thead>
<tr>
<th>Basic Specification</th>
<th>Gold Specification</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>WEBSITE</strong></td>
<td></td>
</tr>
<tr>
<td>Bereavement Service/ mortuary information as part of either page on trust website.</td>
<td>Comprehensive website information with Bereavement Service’s own page.</td>
</tr>
<tr>
<td>Use of plain English (words not acronyms).</td>
<td>Dedicated area on intranet for staff to find ‘after death’ information for carers.</td>
</tr>
<tr>
<td>Clear &amp; visible contact name and details for bereavement office/ mortuary.</td>
<td>Condolences on webpage.</td>
</tr>
<tr>
<td>Links to NHS Choices Bereavement pages.</td>
<td>Online booking service for bereavement office appointments.</td>
</tr>
<tr>
<td>Information on identification requirements for Medical Certificate Cause of Death (MCCD).</td>
<td>Detailed online Information on locality/ Trust specific processes for obtaining MCCD.</td>
</tr>
<tr>
<td>Small selection of links/Signposting to support pages/services.</td>
<td>Large selection of Links/Signposting to support pages/services - local and national.</td>
</tr>
</tbody>
</table>

**ADVICE/SIGNPOSTING/INFORMATION LEAFLETS**

- Basic care after death leaflet, detailing information about bereavement services/ mortuary processes.  
- Advice on arranging Death Certificate (MCCD) and cremation papers including personal identification requirements for collection.  
- Advice on obtaining Funeral Director white form.  
- Advice on process for viewing the deceased.  
- Advice on post mortem and coroner involvement.  
- Provision of a list of local undertakers/Funeral Directors.  
- Advice on how to arrange Religious Beliefs/customs for when death occurs.  
- Detailed information regarding the events at point of death - e.g. exact times, people present.  
- Pro-active communication around delays in the MCCD release.  
- Signposting - Formal Counselling.  
- Signposting - Advice on ‘Tell us Once’ service from the Government/ Council.  
- Signposting - Advice on DWP/benefits.  
- Signposting - Advice on telling children of the death.  
- Signposting - Advice on withdrawing from a Care Home.  
- Signposting - Organ donation procedures explained.  
- Signposting - Liaison with Police/Coroner/GP/Social Worker etc.

**IN-HOSPITAL FACILITIES FOR CAREERS**

- Family rooms available on the ward.  
- Showers and bathrooms available (Public).  
- Free parking when visiting mortuary.  
- Dedicated parking space for viewing/MCCD collection.  
- Access to chaplaincy and spiritual support.  
- Bereavement room/ Quiet Room.  
- Decedent remains on ward until mortuary transport is arranged.  
- Ward staff to proactively support carers at the time of death occurs and advise on immediate arrangements such as last offices, verification of death, personal belongings, how long they can stay with patient.  

**IN-HOSPITAL FACILITIES FOR DECEASED**

- Bereavement Office identifiable on hospital map.  
- All staff are aware of bereavement office location and able to direct to it.  
- Bereavement office readily identifiable from the car parks and hospital corridor.  
- Trust specific bereavement procedure for NOK who lack capacity.  
- Viewing weekdays (9-5).  
- Property and valuables returns bags (polythene).  
- Plastic wallet to hold MCCD and important leaflets.  
- Neutral and non-clinical viewing area in mortuary.  
- Trust policy on transferring the deceased when death occurs in a non-ward area.  

**EDUCATION & TRAINING**

- All Bereavement Team staff have had core Communication Skills Training.  
- All ward staff receive core communication skills in speaking to bereaved relatives.  
- All ward staff receive awareness training to utilise Advance Care Planning information in delivering care at the time of death and into bereavement.  
- All ward staff receive training in cultural differences regarding body preparation.  
- All ward staff receive training in performing last offices.  
- All medical staff to receive training on death certification.  

- All Bereavement Team staff (including clerical) have access to different levels of Communication Skills Training in line with their needs.  
- All ward staff have received the appropriate level of communication skills training required for speaking to bereaved relatives in line with their needs.  
- All appropriate staff receive full training to develop an Advance Care Plan for care at the time of death and into bereavement.  

**Codes**

- [Level 4]
Section 5: Standards

1. 100% of identified main carers of the person who died should be given information regarding the emotional impact of bereavement, coping strategies, practical information and local support services within 48 hours of the death.\textsuperscript{2,7,17} [Grade D]

2. For Specialist Palliative Care Services providing Component 2 or 3 support, families / carers should be made aware that written contact will be made and given the opportunity to decline this service.\textsuperscript{2,7,17} [Grade D]

3. For Specialist Palliative Care Services providing Component 2 or 3 support, proactive or outreach offers of bereavement support should be made 8 to 12 weeks after bereavement.\textsuperscript{2} [Grade D]

4. Each Clinical Commissioning Group and Specialist Palliative Care Service Group should have a protocol of who provides which Component of Bereavement Support.\textsuperscript{2,7,17} [Grade D]

5. All palliative care professionals should receive training about bereavement theory, experience and local service provision every 3 years. [✓]

6. Staff and volunteers providing Component 2 and 3 support should receive specialised training relevant to their area of work on induction and refreshed every 2 years [✓]

7. Volunteers and professionals involved in Component 2 and 3 bereavement support should participate in monthly supervision.\textsuperscript{2,7,17} [Grade D]

Applications and Implications

There is limited economic modelling of the impact of bereavement and it is highly context dependent.

The Cheshire and Merseyside Palliative and End of Life Care Network have resources to support education in implementing this guideline at http://www.cmscnsenate.nhs.uk/strategic-clinical-network/our-networks/palliative-and-end-life-care/audit-group/.

Recommendations for research and service improvement include:

- The type and effectiveness of bereavement support in minority groups
- The effectiveness of population level interventions in improving societal bereavement support (e.g. Compassionate Communities)
- The validity of bereavement assessment tools in predicting those needing Component 2 and 3 support
- The development of bereaved person reported outcome measures that distinguish between natural grief emotions and symptoms suggestive of Prolonged Grief Disorder and Persistent Complex Bereavement Disorder
- The development of interventions for complicated grief or Prolonged Grief Disorder and Persistent Complex Bereavement Disorder
Cheshire & Merseyside Palliative & End of Life Care Strategic Clinical Network
Standards & Guidelines

Acknowledgments and Declarations of Interest

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- Dr Kate Bennett, Reader in Psychology, Department of Psychological Sciences and the School of Psychology, University of Liverpool who was our invited expert
- Dr Marilyn Relf, Bereavement Care Lead, Sir Michael Sobell House, Oxford University Hospitals NHS Trust who was our external reviewer.

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The authors contributed as follows.

Literature Review: AK, JR, GT
Audit Tools: KA, RB, LC, AK, SO, JR, SS, GT
Updating Guidance and Grading Recommendations: KA, RB, LC, AK, SO, JR, SS, GT
Standards: KA, RB, LC, AK, SO, JR, SS, GT
Final writing of manuscript of guidelines: AK (lead), KA, RB, LC, SO, JR, SS, GT
**Review Date**

The guidelines will be reviewed three years after publication as outlined in the Cheshire and Merseyside Palliative and End of Life Care Network Audit Group Guideline Development Manual.

**Appendix 1: ‘Diagnostic’ Criteria for Persistent Complex Bereavement Disorder and Prolonged Grief Disorder[^2][Level 2]**

<table>
<thead>
<tr>
<th>Persistent Complex Bereavement Disorder (DSM V)</th>
<th>Prolonged Grief Disorder (ICD 11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Death of a close other</td>
<td>A. Death of a close other</td>
</tr>
<tr>
<td>B. Since the death, at least one of the</td>
<td>B. Yearning for the deceased daily or to a disabling degree</td>
</tr>
<tr>
<td>following on most days to a clinically</td>
<td>C. Five or more of the following daily or to a disabling degree:</td>
</tr>
<tr>
<td>significant degree for at least 12 months</td>
<td>1. Confusion about one’s role in life or diminished sense of self</td>
</tr>
<tr>
<td>after the death:</td>
<td>2. Difficulty accepting the loss</td>
</tr>
<tr>
<td>1. Persistent yearning for the deceased</td>
<td>3. Avoidance of reminders of the reality of the loss</td>
</tr>
<tr>
<td>2. Intense sorrow and emotional pain in</td>
<td>4. Inability to trust others since the loss</td>
</tr>
<tr>
<td>response to the death</td>
<td>5. Bitterness or anger related to the loss</td>
</tr>
<tr>
<td>3. Preoccupation with the deceased</td>
<td>6. Difficulty moving on with life (e.g., making new friends, pursuing interests)</td>
</tr>
<tr>
<td>4. Preoccupation with the circumstances</td>
<td>7. Emotional numbness since the loss</td>
</tr>
<tr>
<td>of the death</td>
<td>8. Feeling that life is unfulfilling, empty, or meaningless since the loss</td>
</tr>
<tr>
<td>C. Since the death, at least six of the</td>
<td>9. Feeling stunned, dazed, or shocked by the loss</td>
</tr>
<tr>
<td>following on most days to a clinically</td>
<td>D. At least 6 months have passed since the death</td>
</tr>
<tr>
<td>significant degree for at least 12 months</td>
<td>E. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning</td>
</tr>
<tr>
<td>after the death:</td>
<td>F. The disturbance is not better accounted for by major depressive disorder, generalized anxiety disorder, or posttraumatic stress disorder.</td>
</tr>
<tr>
<td>1. Marked difficulty accepting the death</td>
<td><strong>A-F inclusive must be met to reach the diagnosis</strong></td>
</tr>
<tr>
<td>2. Disbelief or emotional numbness over the loss</td>
<td></td>
</tr>
<tr>
<td>3. Difficulty with positive reminiscing about the deceased</td>
<td></td>
</tr>
<tr>
<td>4. Bitterness or anger related to the loss</td>
<td></td>
</tr>
<tr>
<td>5. Maladaptive appraisals about oneself in relation to the deceased or the death (e.g., self-blame)</td>
<td></td>
</tr>
<tr>
<td>6. Excessive avoidance of reminders of the loss</td>
<td></td>
</tr>
<tr>
<td>7. A desire to die to be with the deceased</td>
<td></td>
</tr>
<tr>
<td>8. Difficulty trusting other people since the death</td>
<td></td>
</tr>
<tr>
<td>9. Feeling alone or detached from other people since the death</td>
<td></td>
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<tr>
<td>10. Feeling that life is meaningless or empty without the deceased or the belief that one cannot function without the deceased</td>
<td></td>
</tr>
<tr>
<td>11. Confusion about one’s role in life or a diminished sense of one’s identity</td>
<td></td>
</tr>
<tr>
<td>12. Difficulty or reluctance to pursue interests or to plan for the future (e.g.,</td>
<td></td>
</tr>
</tbody>
</table>
D. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning

E. The bereavement reaction must be out of proportion or inconsistent with cultural or religious norms

**A-E inclusive must be met to reach the diagnosis**
## Appendix 2: Evaluation studies of Bereavement Service Interventions in Adult Hospice and Specialist Palliative Care Adapted from Arthur et al

### NICE Component 1 Interventions

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Foulstone 1993</strong></td>
<td>Australia</td>
<td>Intervention: A six-monthly memorial service bereavement support service within a district hospital palliative care service. Participants &amp; Study Design: Service attendees (n=50) Questionnaire survey. Results: Respondents found memorial service to be a positive experience, particularly in relation to formality and content. One fifth found the service distressing.</td>
</tr>
</tbody>
</table>

### NICE Component 2 Interventions

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diamond 2012</strong></td>
<td>United Kingdom</td>
<td>Intervention: One-to-one bereavement support sessions with a trained peer volunteer. Participants &amp; Study Design: 23 bereaved people and 13 volunteers in two hospices. Results: Bereaved people found these sessions helpful. Themes included: Hope &amp; reassurance derived from the sessions, sharing and continued support from the group was of benefit, positive qualities of the volunteer helped, Exploring options and strategies for living with grief, Focusing on difficult emotions or issues helped.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Marquis 1996</strong></td>
<td>Australia</td>
<td>Intervention: Hospice bereavement service. Participants &amp; Study Design: Bereaved carers (n=30), nurses (n=10) and volunteers (n=10) Qualitative interviews. Results: Family carers wanted continuity by bridging life, death and bereavement. The relationship with staff should be based on reciprocal decision making, starting in the illness phase and continuing into bereavement. Nurses also wanted continued care and felt this help resolve their own issues of grief for the loss of the patient. Nurses needed knowledge but also experience to develop the right skills to deal with bereavement.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relf 2000</strong></td>
<td>United Kingdom</td>
<td>Intervention: Volunteer bereavement care. Participants &amp; Study Design: Bereaved people ‘at risk’ (n=73) Randomised controlled trial. Results: Volunteer support reduced the use of health services.</td>
</tr>
</tbody>
</table>

### NICE Component 3 Interventions
### Appendix 2: Evaluation studies of Bereavement Service Interventions in Adult Hospice and Specialist Palliative Care Adapted from Arthur et al.14

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Description</th>
</tr>
</thead>
</table>
| Agnew 200951 | United Kingdom | **Intervention:** Social worker facilitated group support programme at hospice  
**Participants & Study Design:** Bereaved service users from a hospice (n=7) Focus group (n=1) study  
**Results:** Participants valued attending the group and sharing experiences. It was important participants understood the nature, structure and expectations of the group to attend and ‘feel safe’ in the environment. Participants suggested using informal clear language and large font with bullets points in the information leaflet for bereaved people |
| Kissane 200652 | Australia | **Intervention** 4 to 8 sessions of Grief therapy over 9 to 18 months (pre- and post-death) to enhance family coping with grief compared with standard care  
**Participants & Study Design** Family members at risk of poor outcome (n=363) Multi centre cluster randomised control trial  
**Results** No statistically significant difference in abnormal grief expression |
| Wilkinson 200753 | United Kingdom | **Intervention** Hospice child bereavement support services  
**Participants & Study Design** Parents (19 service-users, 6 non-users) (n=25) Semi-structured interviews  
**Results** Parents used the service for advice and reassurance, to support their children and to ameliorate behavioural difficulties at home or school. Children and parents benefited from talking to a non-family member and being involved in social event that reduced feelings of isolation. Those that did not use the service felt it was not necessary and that they had enough support |

### Mixed NICE Component Interventions

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Description</th>
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</thead>
</table>
| Brown 201554 | Australia | **Intervention:** Bereavement service offering all of:  
1. Bereavement information pack  
2. Condolence card  
3. Telephone call six weeks after death  
4. Offer of face-to-face session  
5. Memorial service six months after death  
6. Name included in Hospital Chapel Memorial Book  
**Participants & Study Design:** 17 bereaved people in four focus groups  
**Results:** Important that service was non-religious in content. Information leaflet, sympathy card, phone call and memorial service consistently valued |
### Appendix 2: Evaluation studies of Bereavement Service Interventions in Adult Hospice and Specialist Palliative Care Adapted from Arthur et al.\(^{14}\)

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Description</th>
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</table>
| Connor 1996\(^{55}\) | USA           | **Intervention:** One year structured bereavement support programme  
**Participants & Study Design:** Spouses (n=354) Audit of inpatient and outpatient service use  
**Results:** Spouses treated with extensive intervention had lower hospital and clinic use than those who received limited intervention or non-intervention |
| Morris 2015\(^{56}\)   | USA           | **Intervention:** Hospital bereavement service  
**Participants & Study Design:** Bereaved carers (n=140), Questionnaire  
**Results:** A formal letter of condolence and written bereavement guide had a positive impact on grieving. Contact from the nurse and oncologist who looked after the person who died was very well evaluated |
| Reid 2006\(^{52}\)     | United Kingdom | **Intervention:** Hospice bereavement services  
**Participants & Study Design:** Staff and Volunteers (n=201) Case studies, focus groups and interviews  
**Results:** Telephone support was perceived as acceptable and cost-effective way of providing follow-up. Running support groups was practically more difficult and resource intensive, drop-in sessions appeared to be more successful. There appeared to be no readily available source of support for people with more complex bereavement issues |
| Roberts 2008\(^{57}\)  | Ireland       | **Intervention:** Hospice bereavement support services  
**Participants & Study Design:** Users and nonusers of bereavement support services (n=243) Postal questionnaire survey  
**Results:** Distress higher among users of services at baseline and follow-up  
Satisfaction levels high |
References


