Bereavement Services Audit
Karen Allen, Rachel Buckle, Laura Chapman, Diane Earl, Andrew Khodabukus, Sue Oakes, Joanna Roberts, Sandra Smith, Grace Ting

14th January 2016
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<td>Proposed Standards &amp; Guidelines</td>
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<td>Dr Laura Chapman</td>
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## Bereavement Guideline Development Group Membership

<table>
<thead>
<tr>
<th>Name</th>
<th>Position &amp; Affiliation</th>
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<tbody>
<tr>
<td>Karen Allen</td>
<td>Acting Principal Social Worker, Marie Curie Hospice, Liverpool</td>
</tr>
<tr>
<td>Rachel Buckle</td>
<td>Clinical Nurse Specialist in Palliative Care, Liverpool Community Health NHS Trust</td>
</tr>
<tr>
<td>Dr Laura Chapman</td>
<td>Consultant in Palliative Medicine, Royal Liverpool and Broadgreen University Hospitals NHS Trust</td>
</tr>
<tr>
<td>Diane Earl</td>
<td>Bereavement Services Coordinator, St Rocco’s Hospice, Warrington</td>
</tr>
<tr>
<td>Dr Andrew Khodabukus</td>
<td>Consultant in Palliative Medicine, Royal Liverpool and Broadgreen University Hospitals NHS Trust</td>
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<tr>
<td>Sue Oakes</td>
<td>Clinical Nurse Specialist in Palliative Care, Liverpool Heart &amp; Chest Hospital Foundation NHS Trust</td>
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<td>Dr Joanna Roberts</td>
<td>Specialty Registrar in Palliative Medicine, Royal Liverpool and Broadgreen University Hospitals NHS Trust</td>
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<tr>
<td>Sandra Smith</td>
<td>Patient, Carer and Public Representative</td>
</tr>
<tr>
<td>Dr Grace Ting</td>
<td>Specialty Registrar in Palliative Medicine, Willowbrook Hospice</td>
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<tr>
<td>Invited Expert</td>
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<tr>
<td>Dr Kate Bennett</td>
<td>Reader in Psychology in the Department of Psychological Sciences and the School of Psychology at the University of Liverpool</td>
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<tr>
<td>Year</td>
<td>Provenance</td>
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</tr>
<tr>
<td>2003</td>
<td>Initial guidelines produced following local audit</td>
</tr>
<tr>
<td>2006</td>
<td>Lead contributor and External expert review</td>
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<tr>
<td>2009</td>
<td>Lead contributor and External expert review</td>
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<tr>
<td>2010</td>
<td>MCCN Bereavement Support Guidelines via End of Life and Palliative CNG (outside Audit Process)</td>
</tr>
<tr>
<td>2015</td>
<td>CMPCNAG Annual Review: majority quorate vote to review guidelines by e-Vote</td>
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**Meetings to date of membership & subgroups of Bereavement Services Guideline Development Group**

- 12th March 2015 – CMPCNAG review meeting and clinical question discussion
- 13th May 2015
- 15th July 2015
- 27th July – presentation to People’s Voice Forum
- 30th September 2015
- 18th November 2015
- 9th December 2015
- 17th December 2015
- 6th January 2016
- 14th January 2016 – presentation and review by CMPCNAG Audit Meeting
Current Standards & Guidelines

14th January 2016
Recognises grief:
• As multi-dimensional
• As a normal response to loss
• In some people requires additional support

Proposes, but does not mandate, a bereavement model (see figure)

Emphasises the importance of bereaved person centred care (including opt out) and education and training for staff
Current Standards

1. All families / carers should receive an information booklet about bereavement and the support available within 72 hours of the bereavement. [Grade D]

2. Families / carers should be made aware that written contact will be made and given the opportunity to decline this service. [Grade D]

3. Proactive or outreach offers of bereavement support should be made 8 weeks after bereavement. [Grade D]

4. Bereaved relatives / carers should be referred on to an appropriate specialist bereavement service where appropriate. [Grade D]

5. Each organisation involved in bereavement support should ensure that providers are adequately trained and supervised. [Grade D]
Bereavement/loss may start from the day of diagnosis where there is no hope of cure.

Recognition that patients and families may cope in different ways during the illness and death.

Role of GP important – Recognition that Signposting needs to be to the most appropriate service.

GPs need to have ready access to information. Needs to be liaison between services.

HCP education, training and fear of talking about death and bereavement impairs bereavement care.
People’s Voice Feedback

5. **Disparate families.** Services are currently based on the location of the deceased. Worries about leaflets. What’s written in them and giving them out to people – *ensure they are sensitive*

6. Very concerned about bereavement services for complex bereavement reactions. There are *very long waiting lists for general bereavement services*. Postcode lottery for services

7. **How many people are we missing with complicated grief?** ‘If we can’t help them at the stage that they need help they often stop living and the bereavement takes over their lives’.

8. Peers often know more than general professionals. They have real life experience and can help more e.g. volunteers. One delegate though that *volunteers were better than professionals*. 
9. Health economics. There is a cost of not having this in place. Can be tricky to find evidence to present in the argument.

But also...

Not a bottom less pit. Need to spend money in a correct way at interventions that work. If have time off work there is a cost as well. This returns to normalisation of death and bereavement. Normal to grieve
Invited Expert – Dr Kate Bennett
Bereavement Concepts

14th January 2016
Bereavement Concepts

- Importance of individual experience
- Continuing bonds
- Dual Process Model of bereavement
- Resilience, coping and vulnerability
- (Identity: wife to augmented wife/widow; masculinity & bereavement expectations; LGBTQI [Bennett, 2007; Bennett, 2010; Piatczany et al., 2015])
- (Meaning making [Neimeyer, 2005])
## Important Distinctions

<table>
<thead>
<tr>
<th>Bereavement</th>
<th>The state or condition caused by loss through death</th>
</tr>
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<tbody>
<tr>
<td>Grief</td>
<td>The sorrow, hurt, anger, guilt, confusion, or other feelings that arise after a loss</td>
</tr>
<tr>
<td>Mourning</td>
<td>The way we express our grief - Mourning is heavily influenced by cultural norms</td>
</tr>
</tbody>
</table>

**Distinguishing between Bereavement and widowhood**

- Often bereavement and widowhood are used interchangeably.
  - However, it is important to distinguish between them
- Bereavement is the objective situation or state of having experienced the death of someone significant in one’s life;
  - It is considered to be a relatively short-term state
  - Has primarily personal consequences and meanings.
- Widowhood is an ongoing, and frequently long-term state, which has social and personal consequences and meanings.
Individual Experience

- Gender
  - Evidence is mixed - variable dependent
- Age
  - Evidence is mixed - influenced by additional responsibilities not age
- Culture
- Disenfranchised grief
- Social Support
  - Lower levels of social support lead to lower levels of wellbeing
- Expected/Sudden
  - Evidence is mixed
  - Poor copers were more likely to have had a spouse who was unwell before their death but whose death was unexpected (Bennett, 2004)
- Caregiving
  - Evidence is mixed
Counter to traditional bereavement theories which emphasised the severing of ties with the deceased

Klass et al. 1996 emphasise the importance of maintaining the bond with the deceased

There is evidence that this is what many people do naturally
  - Continuing bonds
  - Loosening of the bonds (Bennett, 2010)

Schut et al. (2006) suggests may be important to disentangle continuing bonds from grief intensity

I also wonder (I have not yet studied this empirically) whether the relationship between continuing the bond (or not) and wellbeing may be complex
  - Too loose a bond may be problematic but so too might be too tight a bond
Dual Process Model of Bereavement

Everyday life experience

Loss-oriented
- Grief work
- Intrusion of grief
- Breaking bonds/ties/relocation
- Denial/avoidance of restoration changes

Restoration-oriented
- Attending to life changes
- Doing new things
- Distraction from grief
- Denial/avoidance of grief
- New roles/identities/relationships

Stroebe & Schut, 1999
Dual Process Model

Oscillation
- This is the swinging back and forth between loss- and restoration-oriented coping
- Evidence that loss is more common earlier, and restoration later, although both continue (Richardson, 2007)
Participants

- 91 (46 women; 45 men)
- Two Qualitative Questions: What did you do?; How did you feel?

Coping or psychological adjustment

- Assessed as coping well or not (3 independent assessors)
- Coping poorly - 14 women, 12 men
- Coping well - 32 women, 33 men

Fitting existing codes into the DPM: $\chi^2$ analysis – how often a code was reported by coping status
## Dual Process Model

<table>
<thead>
<tr>
<th></th>
<th>Coping ( \chi^2 )</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Loss</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intrusion</td>
<td>Yes 44, No 21</td>
<td>6.58</td>
</tr>
<tr>
<td><strong>Restoration</strong></td>
<td>Yes 40, No 25</td>
<td>5.42</td>
</tr>
<tr>
<td>New Roles</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th></th>
<th>Coping ( \chi^2 )</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Loss</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidance of</td>
<td>Yes 10, No 55</td>
<td>16.68</td>
</tr>
<tr>
<td><em>Change</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restoration</td>
<td>Yes 12, No 53</td>
<td>4.05</td>
</tr>
<tr>
<td>Distraction</td>
<td></td>
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</tr>
</tbody>
</table>

**Notes:**
- \( \chi^2 \) values indicate statistical significance at the specified p-values.
Research has focused on responses to bereavement and this has been conceptualised in different ways:

- Copers vs non-copers (Bennett et al. 2005)
- Resilient, chronic grief, chronic depression, depressed improved (& common grief) (Bonnano et al., 2002, 2004, 2012)
- Resilient vs non-resilient (Bennett, 2010)
- Resilients, copers, Vulnerables (Spahni et al., 2015)

Broadly, these can be seen as those who do well, those who get by, and those who do not.
Resilience, Coping and Vulnerability

Resilience as a steady state

– Without fluctuating levels of distress following bereavement (Bonanno, 2004)

Resilience as a long-term outcome

– Initial painful awareness of loss; integrated belief and value system; optimistic and positive personality (Moore & Stratton, 2003)

– Bennett’s criteria: they viewed their current life positively; they were currently actively; participating in life; they had returned to a life that had meaning and satisfaction; and they were coping (2010).
Resilience, Coping and Vulnerability

- N = 60 widowers: 23 – resilience; 16 not coping; 21 not meeting criteria
  - 3 met Bonanno’s criteria (13% of the resilient widowers).
  - 9 men achieved resilience gradually (39%).
  - 8 achieved resilience a turning point (35%).
  - 3 men resilience through the two trajectories (13%).
- Timing crucial, help rejected if too early, but risks if offered too late
- Agency
  - Widowers as active agents: Doing something to change their situation
  - Others as agents, widowers as passive: Decisions taken for widowers, or being forced by others to change
It is possible that Bonanno’s conceptualisation of resilience fits into Moore & Stratton’s and Bennett’s:
Bonanno et al. (2004)
CLOC data
86% (n=276) one + follow-up interview (6mth)
64% (n=205) both follow-up interviews (18mth)
185 widowed persons (161 women and 24 men)

Figure 1. Patterns of depression, as measured by Center for Epidemiologic Studies Depression (CES-D) scores from preloss to 18 months (mo.) postloss (N = 185).
Resilience, Coping and Vulnerability

**Figure 4.** Group differences in comfort from positive memories of the spouse at 6 and 18 months (mo.) of bereavement.

**Figure 5.** Group differences in perceived/remembered marital adjustment at 6 and 18 months (mo.) of bereavement.
Resilience, Coping and Vulnerability


Fig. 1. 4-class unconditional trajectory model of CES-D scores (N = 301).
Spahni et al. (2015)

n = 402 (228 women, 174 men); widowed ≤ 5 years, mean age= 74.41

Exploratory latent profile analysis
Resilience, Coping and Vulnerability

Fig. 2. Centred means by profile of the best-fitting model of widowed respondents. ** p < 0.01; *** p < 0.001.
## Table 4. Means, standard errors and $\chi^2$ test of distal variables in the bereaved profiles

<table>
<thead>
<tr>
<th>Variables</th>
<th>Resilients (n = 215)</th>
<th>Copers (n = 155)</th>
<th>Vulnerables (n = 30)</th>
<th>Wald’s test approx. $\chi^2$</th>
<th>$\omega$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>values</td>
<td>SE</td>
<td>values</td>
<td>SE</td>
<td>values</td>
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<tr>
<td><strong>Sociodemographic variables</strong></td>
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<tr>
<td>Age</td>
<td>73.84</td>
<td>0.49</td>
<td>75.31</td>
<td>0.58</td>
<td>73.79</td>
</tr>
<tr>
<td>Gender (women)</td>
<td>61%</td>
<td>–</td>
<td>50%</td>
<td>–</td>
<td>61%</td>
</tr>
<tr>
<td>Education</td>
<td>3.67</td>
<td>0.09</td>
<td>3.61</td>
<td>0.11</td>
<td>3.27</td>
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<tr>
<td><strong>Intrapersonal resources</strong></td>
<td></td>
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<tr>
<td>Extraversion</td>
<td>3.53</td>
<td>0.06</td>
<td>2.85</td>
<td>0.07</td>
<td>2.30</td>
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<tr>
<td>Neuroticism</td>
<td>2.30</td>
<td>0.06</td>
<td>2.96</td>
<td>0.07</td>
<td>3.61</td>
</tr>
<tr>
<td>Conscientiousness</td>
<td>4.38</td>
<td>0.04</td>
<td>4.02</td>
<td>0.06</td>
<td>4.07</td>
</tr>
<tr>
<td>Agreeableness</td>
<td>3.79</td>
<td>0.05</td>
<td>3.52</td>
<td>0.06</td>
<td>3.44</td>
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<tr>
<td>Openness</td>
<td>3.76</td>
<td>0.07</td>
<td>3.33</td>
<td>0.08</td>
<td>3.02</td>
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<tr>
<td>Resilience</td>
<td>5.87</td>
<td>0.05</td>
<td>5.15</td>
<td>0.07</td>
<td>4.26</td>
</tr>
<tr>
<td><strong>Interpersonal resources</strong></td>
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<td></td>
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<td></td>
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<tr>
<td>Social support (available)</td>
<td>76%</td>
<td>–</td>
<td>75%</td>
<td>–</td>
<td>61%</td>
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<tr>
<td><strong>Marriage context</strong></td>
<td></td>
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<tr>
<td>Time married</td>
<td>45.23</td>
<td>0.64</td>
<td>45.16</td>
<td>0.75</td>
<td>42.82</td>
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<tr>
<td>Marital happiness</td>
<td>8.39</td>
<td>0.14</td>
<td>8.29</td>
<td>0.17</td>
<td>8.21</td>
</tr>
<tr>
<td>Spousal support</td>
<td>4.38</td>
<td>0.06</td>
<td>4.07</td>
<td>0.09</td>
<td>3.97</td>
</tr>
<tr>
<td><strong>Death context</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since loss</td>
<td>3.44</td>
<td>0.09</td>
<td>3.14</td>
<td>0.11</td>
<td>3.05</td>
</tr>
<tr>
<td>Expectedness (foreseen)</td>
<td>61%</td>
<td>–</td>
<td>64%</td>
<td>–</td>
<td>50%</td>
</tr>
<tr>
<td>Emotional valence</td>
<td>3.96</td>
<td>0.21</td>
<td>3.67</td>
<td>0.23</td>
<td>2.64</td>
</tr>
</tbody>
</table>

Values are given as means or %. * p < 0.08; ** p < 0.05; *** p < 0.01; **** p < 0.001; effect size is calculated with the formula $\omega = (\chi^2/N)^{1/2}$. 

Cheshire and Merseyside Strategic Clinical Networks
Resilience, Coping and Vulnerability

• Bennett et al. (submitted)
• Longitudinal follow-up of Spahni paper
  • Stability in profiles
  • Stability in membership
  but
  • Some people move to a more adapted class, whilst others move to a less adaptive one
• Facilitating adaptation: younger, longer time since widowhood, new life perspectives and a less dependent spouse
• Less adaptive profiles: women, older, more recently bereaved, and more dependent spouses.
• Path to adaptation not always smooth, complex inter- and intra-individual factors associated with the trajectories of adaptation.
Identity and Meaning Making

• To be discussed if time
Bereavement Literature Review
Bereavement Literature Review

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]?
Bereavement Literature Review

Systematic review of literature commissioned by Department of Health

Addressed Need, Provision, Effectiveness and Cost of Bereavement Services

PRISMA – covered majority of areas – high methodological quality

Bereavement GDG updated this search from 2010 to 2015 and ran an all years search to include specialist palliative care search terms
Medline (n=325)  
CINALH (n=269)  
EMBASE (n=5)  
Cochrane (n=35)  
Other (n=160)

Total (n=794)

Exclusions of abstracts and titles (n=735)

Exclusions full text (n=22)
- Non evaluative study of bereavement service in SPC populations 8
- Non systematic review 3
- Editorial 1
- Non SPC Services 7
- Paediatric deaths 1
- Descriptive study 1
- Guideline – did not meet AGREE criteria 1

Articles selected for full text review (n=58)

Duplicates inc those already reviewed by Arthur et al (n=51)

Studies included in the Arthur review (n=88)

Studies included in the updated review (n=4)

Palliative Care MeSH Terms & keywords
- Palliative Care
- Palliat*
- Hospice
- Terminal Care
- Terminal Illness
- End of Life Care

Bereavement MeSH Terms & keywords
- Bereavement
- Bereave$6
- Grief
- Loss
- Health Services
- Servic1
- services

Date Run
All years for combined search to August 2015 and 2010 to August 2015 for review of just bereavement service literature
Results

1. Need
2. Provision  Interspersed with examples of the impact of bereavement
3. Effectiveness
4. Cost

<table>
<thead>
<tr>
<th>Levels of evidence/ Description of the evidence</th>
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<tbody>
<tr>
<td>1+++</td>
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<tr>
<td>1+</td>
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<tr>
<td>1-</td>
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<tr>
<td>2++</td>
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<tr>
<td>2+</td>
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<td>2-</td>
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<tr>
<td>3</td>
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<tr>
<td>4</td>
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</tbody>
</table>
1. Need

Friends and family are the main source of support for most people [Level 2+]

Many report that they do not need formal bereavement support services [Level 2+]

Increased need for formal bereavement support is associated with:

• The lower availability of social support [Level 2+]
• If a spouse or partner is bereaved [Level 2+]
• Traumatic or sudden death [Level 2-]

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1. Need

Formal risk assessment tools can raise awareness of need among service providers for ongoing support but

- their ability to accurately predict who will benefit most is unproven [Level 2++]
- there is a risk of over-reliance on structured measures of assessment. [Level 4]

It is important not to underestimate the ability of those who are bereaved to judge the extent of their need for formal support. [Level 2+]

Offers are important but only a minority of bereaved people will take up offers of bereavement services. [Level 2+]

1. Need

Bereavement – in particular complicated grief/prolonged grief disorder is associated with:

- excess risk of mortality (e.g. through higher risk behaviours like smoking) \(^{ix, x}\) [Level 2++]
- increased use of health services \(^x\) [Level 2++]
- subsequent worse mental and physical health \(^x, xi\) [Level 2++]

There is an absence of evidence of substantial unmet need. [Level 4]

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1. Need

Users of bereavement services when compared to non-users have greater problems of adaptation to loss. \[^{VI}\] [Level 2-]

Where services are accessed, people express the need for:

- Information to help them decide \[^{xii-xiv}\] [Level 2+]

- support from services involved in the care of the person who died continuing with bereavement support after death \[^{xiv-xxi}\] [Level 2+]


"I started my grieving at diagnosis, for the lost future happiness and also the dread of the immediate future. When my partner passed away I felt relieved and guilty that he was no longer suffering. People perceived I was not suffering bereavement because I was relieved he was not suffering and therefore I was given no support."
2. Provision

The majority of bereavement services are provided by hospice and palliative care services. There are fewer studies of services in acute and non-specialist community settings. xxii-xxiii [Level 4]

Provision can be loosely categorised into three levels of intensity:

1. acknowledgement and information based services
2. one to one support and/or peer support
3. more intensive therapeutic and structured bereavement interventions for more complex grief reactions. xxii-xxv

"My Daughter in Law was offered bereavement counselling when she lost her husband aged 39 to MND. As his mother there was nothing for me. You do not expect your son to die before you especially seeing him waste away and his life cut short so cruelly to MND"
2. Provision

Many bereavement services within the NHS have evolved sporadically. There is a lack of routinely available information to monitor

- uptake
- throughput
- follow-up
- onward referral xxii-xxiii

There is a dearth of evidence relating to bereavement support in care homes, those with a learning disability, black and minority ethnic groups, LGBTQI groups

General practitioners and community staff play a key role bereavement care xiii, xxvi [Level 4]
"I was only the Step daughter and my GP was not really supportive. I believe because I was not a blood relative I still loved him and miss him"
3. Effectiveness

Generally, satisfaction among users of bereavement care services is high. [Level 1-] xxvii-xxx

The strongest evidence is for targeted and specific intervention for people with more complex grief reactions. [Level 1-] xxvii-xxx

There is good evidence that the use of intensive bereavement interventions universally does not alter bereavement outcomes. [Level 1-] xxvii-xxx

There is good evidence to show that motivation on the part of the bereaved is required for bereavement care interventions to be effective. [Level 1-] xxvii-xxx

3. Effectiveness

Overall the evidence for effectiveness is based on studies with methodological flaws including small sample sizes, inadequate control groups and non-random assignment. [Level 1-] xxvii-xxx

The acceptability and appropriateness of support groups is largely dependent on bringing together people with similar attributes and grief experiences. [Level 1-] xxvii-xxx
4. Cost

Costs of bereavement services are poorly documented primarily due to the delivery being the responsibility of a range of service providers working in diverse settings and different sectors. \(^{XXXI}\) [Level 2-]

- Bereavement support provided by volunteers is not without cost but there are challenges in identifying what those costs are.

- Costs for bereavement services are likely to be highly sensitive to how services are delivered, who delivers them, and the context of that delivery.

Weak evidence suggests that trained volunteers have the potential to deliver cost effective bereavement interventions though this is dependent on targeting those who will benefit the most. \(^{XXXI}\) [Level 2-]

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Interventions for supporting informal caregivers of patients in the terminal phase of a disease had a secondary outcome
• The impact on caregiver bereavement following intervention to support the relatives of people who are dying

1. Kissane 2006: Family grief therapy before and after death targeted to families at higher risk of poor outcome.
   • no difference between those experiencing more morbid forms of distress and depression and the control group

2. Walsh 2007: groups were similar in the intensity of bereavement grief experienced (NB intervention took place before death)
Guidance on Cancer Services

Improving Supportive and Palliative Care for Adults with Cancer

The Manual

Future Plans
Draft scope out for consultation until 29.01.2016
Update due in January 2018
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.
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 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.
A minority of people will require specialist interventions.

This will involve:
- mental health services,
- psychological support services,
- specialist palliative care services
- general bereavement services

It will include provision for meeting the specialist need of bereaved children and young people.
Organised around the NICE Components

- Service delivery
- Education & training
- Supervision

Key Performance Indicators

- 100% identified main carers of deceased given information regarding emotional impact of bereavement, coping strategies, practical information and local support services provided within 48 hours of the death

- 80% people accessing component 2 services offered intervention within a maximum of 8 weeks after death
Key Performance Indicators continued

- 80% people referred to component 3 services offered intervention within existing service/contractual standards (locality commissioners will specify expected waiting times for any Component 3 service they commission)

- Survey of bereaved carers experience undertaken biennially (VOICES or similar). Providers should review the feedback given by local patients through this survey and address any areas requiring development that emerge.
1. Planning

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

2. Awareness & 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.

3. 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.
4. Support and Supervision

- Services provide access to support and supervision to ensure safe working practice and afford staff and volunteers the opportunity to recognise the impact of this work on them.

5. Education & Training

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

6. Resources

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

7. Monitoring & Evaluation

- Services continually review the support offered to ensure they are meeting the needs of bereaved people and to inform developments in the service.
National Bereavement Services

NHS choices
www.nhs.uk
Support after Loss of a Child

Child Bereavement UK
REBUILDING LIVES TOGETHER

The Compassionate Friends
Supporting Family After a Child Dies

Child Death Helpline
We're here to listen

Rosie Crane Trust
SUPPORTING BEREAVED PARENTS
Support for Bereaved Children

Child Bereavement UK
REBUILDING LIVES TOGETHER

Winston's Wish
the charity for bereaved children
Acknowledges that grief is individualised but offers advice on:

- Working through grief
- Self help strategies for bereaved people
- Offers leaflets and cards advising on how to help bereaved people.

Dying Matters
“Two Years, One month, Four days”

Sue Ryder offering a new online community and support to help people who are struggling with bereavement.

Sharing experiences of bereavement has a positive impact on how long it takes people to feel better.
Proposed Standards & Guidelines

14th January 2016
Bereavement Services in Palliative Care 2016 Guidelines

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Summary of Main Recommendations

- 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.

- Although grief is a normal, for some it may be more challenging and be associated with significant anxiety and depression. [Level 1++] (March 2007, Gurney 2009) Early identification of individuals who may develop this is important. [Level 1++]

- All health-care practitioners have a role to play in bereavement support before, during and after death. Bereavement Care Standards (2010)

**Care before Death**

- Bereavement experiences can be affected by caring for the dying person and those important to them during the dying phase (Cherlin 2007, Currow 2008). Continuity of care, and the ‘bridging of life and death’ contributes to effective support. [Level 2]

- 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. [Level 2++]

**Assessing Bereavement Need**

- 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. [Level 2++]

**Care at and After Death**

- Bereavement care should move as seamlessly as possible into bereavement support. [Level 1]

- Bereavement experiences can be affected by caring for the dying person and those important to them during the dying phase (Cherlin 2007, Currow 2008). Continuity of care, and the ‘bridging of life and death’ contributes to effective support. [Level 2]

- 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. [Level 2++]

**Component 1 – Universal Support**

- The initial contact regarding bereavement support should be made by the clinical team involved in caring for the dying person. NICE 2004, MCCN Guideline 2010 [Level 1]

- All bereaved people, independent of where the bereavement occurs, should receive an information booklet regarding emotional impact of bereavement, and the services including:
  - information regarding emotional impact of bereavement,
  - coping strategies,
  - practical information about what happens after someone dies
  - how to access local and national services. [Level 1++]

**Component 2 – Selective Support**

- Bereavement care should move as seamlessly as possible into bereavement support. [Level 1]

- Bereavement experiences can be affected by caring for the dying person and those important to them during the dying phase (Cherlin 2007, Currow 2008). Continuity of care, and the ‘bridging of life and death’ contributes to effective support. [Level 2]

- 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. [Level 2++]

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- Bereavement care should move as seamlessly as possible into bereavement support. [Level 1]
Guidelines
General theme of the guidance to include greater emphasis on Component 1 and Public Health

Standards
Obligation for training for all. What timeframe (NB CQC ask for records of evidence of bereavement training in the last 24 months).
Should all specialist palliative care services offer contact at 8 weeks or just those that offer a formal bereavement service? [resource issue vs. EoLC Model]
Add a standard for public health engagement (e.g. annual participation?)

Reaudit
2018?