

Bereavement care service standards 2013



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Foreword to Bereavement Care Service Standards 2013

I am delighted to provide the foreword for this report which is an important and valuable contribution by Cruse Bereavement Care (Cruse) and the Bereavement Services Association (BSA) to the work being done to improve bereavement care services nationally.

We know that the manner in which services, professionals and volunteers respond to those who are bereaved can have a long term impact on how they grieve, their health and their memories of the individual who has died. In our End of Life Care strategy and in the work done on the National End of Life Care programme, we set out the importance of high quality bereavement services in improving the experience of care at the end of life.

Building on this work, and alongside work being done by NHS England on improving the quality of bereavement services, these service standards define a set of quality criteria that represent what professionals, patients and their families have said they would like to see from bereavement care services. I believe they are an important milestone towards ensuring that people who are grieving are able to access high quality, expert support when they need it.

In particular, I hope that by embedding expertise on issues of death, dying and bereavement, these standards will make it easier for professionals, patients and family members across the country to have the necessary conversations to aid proper end of life care planning.

I would like to thank Cruse and the BSA for the work they have done to develop these standards and I hope that the partnerships that have been developed as part of this project will continue to bear fruit as we pursue our common aim of promoting the provision of high quality bereavement services across the country.

John Rouse
Director General for Social Care
Local Government & Care Partnerships

This document is endorsed by the National Bereavement Alliance, and we would like to thank the Alliance members for their consideration of these Standards during their development.

National Bereavement
————— *Alliance*

Preface

In 2007, a Department of Health grant was awarded for the Bereavement Care Pathways Project: a partnership initiative between Cruse and the BSA, which looked at bridging the 'gap' experienced by bereaved people between bereavement services in the statutory and voluntary sectors. Grief is a natural process and this project highlighted that support can be effectively provided in different settings and in a range of ways, to meet diverse needs over time. Following on from that project, a further grant from the Department of Health was awarded to Cruse and BSA for the 'Gold Standard Bereavement Care Project', aiming to build on the foundations of the earlier work in a number of ways, including the revision of existing standards for bereavement care.

These new standards have been developed through:

- The work of the 'Gold Standard Bereavement Care Project' steering group
- A national stakeholder event, bringing together representatives from statutory, voluntary and commercial sectors
- A review of existing literature
- Consulting a range of key people in the field and then members of the National Bereavement Alliance

Context and background

The creation of the Bereavement Care Standards: UK Project (2001) was seen as a landmark event. Their publication consolidated a large amount of work that had been undertaken over a number of years. It was expected that these would then be implemented and used to have an impact on services for bereaved people. But for a variety of reasons, it has been difficult to ascertain exactly whether and how widely they have been used.

In order to be able to understand the current context more fully, please see Appendix 1 for details of relevant initiatives and events in recent years.

These have created a broad canvas against which to set this current work and a heightened awareness of the impact and need for bereavement care in a wide variety of settings (such as hospital, hospice, community, commercial and bereavement support organisations etc). There is a greater level of engagement in the field of bereavement and bereavement care, with a growing collective will to improve current practices and attitudes. This is concurrent with an increasing concern with safety and the 'drivers' who see the closer regulation and oversight of many of the 'talking therapies' as imperative. The Professional Standards Authority (PSA) is undertaking major work to incorporate many therapies and provide a more accountable structure through which they can flourish and join the longstanding accountability of other caring professions. It is encouraging that a new era advocating compassion, evidence based best practice, accountability and good governance seems to be emerging amongst these professional groups.

Whilst there have been some significant developments in bereavement care, the impact of these is as yet largely unknown and there is no tool to enable the quality of services offered to be checked or assessed with any degree of objectivity or uniformity.

The new standards aim to set out what areas need to be addressed in order for services to be both safe and effective in meeting the needs of bereaved people. They apply to all services providing bereavement support in any sector (hospital, hospice, community, commercial and bereavement support organisations including peer support groups), providing a practical tool against which to benchmark what they offer, as well as service development planning and improvement. Implicit in them is acknowledgement of the variety of ways in which support can be provided to bereaved people at various points on the bereavement pathway.

It is hoped that this current update of the standards will provide a framework against which organisations can appraise, develop and improve their services.

First it is important to understand where these new national standards for bereavement care services will fit within a larger framework.

The New National Standards for Bereavement Care Services:-

- Set the criteria for what clients, carers, staff and volunteers can expect from Bereavement Care Services.
- They will facilitate the audit of Bereavement Care Services, and ensure equality and governance across different services.
- They will enable quality control measures to be utilised within the field so that 'minimum standards' become the accepted norm.
- They will lead to a more integrated approach to the delivery of bereavement care, whilst at the same time being adaptable and responsive to the diversity of local services and individual needs.
- They will provide a helpful benchmark for services to be compared across the country.

Local Service standards: produced by each individual service. They set the criteria for how bereavement standards will be applied within that particular service, given their own style of provision and delivery.

Competencies in bereavement care: which describe and assess the competence of individual staff to provide bereavement care at a variety of levels need to be developed so there is greater consistency of skills and training (A comparable piece of work was undertaken by Marie Curie in 2003 in establishing its 'competencies for spiritual care' for palliative care staff). These are similar to occupational standards and should relate to any person working within the field.

Fundamental principles for Bereavement Care Services

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 non-discriminatory 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.

Standards

The framework used to structure these standards falls under 7 headings. Each one is of equal worth and significance – the numbering is only for ease of referencing. The fundamental principles implicit within them have already been described. The attempt to establish three levels recognizes that every service will seek to meet at least the minimum standard, (i.e. level 1) and will need to consider what the standards mean for them in practical terms so staff/ volunteers can deliver a safe and effective service.

It is recognised that many organisations and individuals will be adopting these standards alongside other professional standards and codes of practice: the new standards are designed to supplement other work, but with specific reference to bereavement.

It is expected these standards will be used to benchmark services and services will be expected to endorse the standards as a framework for good practice, and give an indication of how they are to be used in auditing practice, as a condition of membership of the National Bereavement Alliance. It is expected that commissioners will use them as a quality measure.

The challenge now is to disseminate the standards as widely as possible, so that they are taken up and implemented by organisations working in the area of Bereavement Care.

Standard	Levels
<p>1: PLANNING</p> <p>Services have plans in place to address the needs of the client group/community they serve in the most appropriate way.</p>	<ol style="list-style-type: none"> 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.
<p>2: AWARENESS AND ACCESS</p> <p>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.</p>	<ol style="list-style-type: none"> 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.
<p>3: ASSESSMENT</p> <p>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.</p>	<ol style="list-style-type: none"> 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.
<p>4: SUPPORT AND SUPERVISION</p> <p>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.</p>	<ol style="list-style-type: none"> 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.

<p>5: EDUCATION AND TRAINING</p> <p>All staff and volunteers who come into contact with bereaved people have the necessary skills and knowledge to provide support to these people.</p>	<ol style="list-style-type: none"> 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.
<p>6: RESOURCES</p> <p>Resources are allocated so they are responsive to the differing needs of bereaved people.</p>	<ol style="list-style-type: none"> 1. Service provides designated areas and resources for providing bereavement care . 2. Service provides access to communication support eg interpreters. 3. Service provides appropriate ratios of staff/volunteers to bereaved people, especially in relation to vulnerable and young people.
<p>7: MONITORING AND EVALUATION</p> <p>+Services continually review the support offered to ensure they are meeting the needs of bereaved people and to inform developments in the service.</p>	<ol style="list-style-type: none"> 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.

The place of the standards within a framework of service development.

These new standards are just part of a process which encompasses 4 distinct phases (described below) so that an overview of the 'landscape' can be grasped at the outset. This simply seeks to set out a 'normal process' map which will be familiar to many already working within different organisations.

1. To identify/describe services and processes
2. To audit those services and evaluate progress and identify gaps in provision
3. To develop services in line with the above findings
4. To create or contribute to a research agenda so that services may be evidence based and effective using research findings that are disseminated in a way that makes them accessible to service providers.

APPENDIX 1

It is worth recognising some of the initiatives in the recent past to be able to understand more fully the current context and these are detailed below. It should be noted that this is not an exhaustive list.

- 2000: the inquiry into paediatric cardiac surgery at Bristol Royal Infirmary which led onto the Alder Hey Inquiry about retained organs.
- 2001 Bereavement Care Standards: UK project publishes the first standards.
- 2001 Childhood Bereavement Network checklist for good practice in services for bereaved children.
- 2004: Passing of the Human Tissue Act following the retained organs inquiry of 2000
- 2004: Publication of NICE guidelines on “Improving supportive and palliative care for adults with cancer”, which advise on what cancer patients, their families and carers might need and include paying attention to the needs of bereaved people.
- 2005: The establishment of the Bereavement Services Association with Department of Health support, with a remit to create a network for all those who provide bereavement support services primarily within the NHS.
- 2005: Department of Health issue guidance on bereavement care in acute hospitals entitled ‘When a Patient Dies’.
- 2006: The Liverpool Care Pathway was recommended by the Department of Health as the best practice model for care of the dying, referred to again in 2008 and 2009.
- 2006: Peter Wimpenny et al. produced a landmark ‘literature review on bereavement and bereavement care’. It reports on a systematic review of bereavement and bereavement care and highlights the need to develop evidence based practice.
- 2007: The Department of Health commences The Process of Improving Death Certification in England and Wales to revise the whole process of death certification following the Shipman experience.
- 2007: The Department of Health grant was awarded for the Bereavement Care Pathways Project, a partnership initiative between Cruse Bereavement Care (Cruse) and the Bereavement Services Association (BSA) which looked at bridging the gap between bereavement services in the statutory and voluntary sectors.
- 2008: The End of Life Care (EoLC) Strategy was launched and aimed to bring about improvement in access to high quality care for all adults approaching the end of their life.
- 2009: Northern Ireland Health and Social Care Services strategy for bereavement care was published. This framework for bereavement across the two spheres, aims to promote an integrated, consistent approach to all aspects of care across the public and social care services
- 2010: ‘Guidance for Bereavement Needs Assessment in Palliative Care’ was published by Help the Hospices. That work, authored by Marilyn Relf, Linda Machin and Nikki Archer, looks at the rationale for assessing need and explores the inherent problems within this area.
- 2011 NICE (National Institute for Health and Clinical Excellence) Quality Standard for End of Life Care for Adults.
- 2011 Bereavement Care Services: A synthesis of the literature. Department of Health. University of Nottingham.
- 2011: Shaping Bereavement Care was published in Scotland. This identifies basic principles that should guide the provision of bereavement care services.
- 2011: Guidance for staff responsible for care after death (last offices) was written by the national nurse consultant group (palliative care) and the national end of life care programme which was endorsed by the Royal College of Nursing and the Royal College of Pathologists. This guidance provides a standardized template for the last care provided to those who have died and their carers.
- 2011 ‘When a Person Dies’, an update of the 2005 ‘When a Patient Dies’ was commissioned by the Department of Health and supported by the Bereavement Services Association. This provides guidance on end of life and bereavement care in various care settings.
- 2012 the emergence of the National Bereavement Alliance bringing together a national forum for stakeholders on bereavement and providing a national voice on bereavement issues.
- 2013 The responsibility for end of life care passes to the National Commissioning Board.

Gold Standard Bereavement Care Project Steering Group Members

Dr Dawn Chaplin (Joint Chair of the Steering Group) – Head Nurse for Patient Experience and Clinical Dean for Nursing, Heart of England NHS Foundation Trust ands Co-Chair of the BSA

Debbie Kerslake (Joint Chair of the Steering Group) – Chief Executive, Cruse Bereavement Care

Anne Chalmers – Chief Executive, Child Bereavement UK

Rev. Dr Derek J Fraser – Chaplaincy and Bereavement Care Lead, Cambridge University Hospitals and Co-Chair of the BSA

Catherine Betley – Director of Services, Cruse Bereavement Care (until July 2012)

Equalities Adviser – Yunus Dudwala, Head of Chaplaincy and Bereavement Services, Newham University Hospital NHS Trust

List of Consultees

Those who participated in the original stakeholder day in 2010 and, or have contributed to the drafting of the Standards:

Surname	Forename	Job title	Organisation
Archer	Nikki	Supportive Care Manager	St Giles Hospice Association of Bereavement Service Coordinators in Hospice and Palliative Care
Birrell	John	Convenor	Scottish Grief and Bereavement Hub
Brocklehurst	Tanya	Clinical Bereavement Coordinator	The Hospice of St Francis and Mount Vernon Cancer Centre
Charlton	Jo	Bereavement Care Coordinator	Bereavement Services Association
Chapman	Simon	Director of Public and Parliamentary Engagement	National Council for Palliative Care
Cook	Mollie	Lead Counsellor Practitioner	Children's Services, Guy's and St. Thomas' Foundation Trust and Bereavement Research Forum
Coyle	Anne	Area Bereavement Coordinator	Southern Health and Social Care Team
Davenport	Ted	Business Development Manager	RNS Publications
Dechamps	Andrea	Director of Social Work, Bereavement and Welfare	St. Christopher's Hospice
Dowdeswell	Helen	Commissioning Manager	Cruse Bereavement Care
Dudhwala	Yunus	Head of Chaplaincy and Bereavement Services	Newham University Hospital NHS Trust
Elms	Georgia	Chairman	WAY Widowed and Young
Fuller	Alice	Policy and Parliamentary Affairs Office	National Council for Palliative Care
Gall	Ishbell	Chair	Association of Anatomical Pathology Technology Barchester Healthcare
Gallacher	Elizabeth	Care Specialist	Bereavement Services Alliance Member
Goss	Sam	Mortuary Manager	Salisbury NHS Foundation Trust Association of Anatomical Pathology Technology
Griffith	Kathryn	Bereavement Service Manager	Bereavement Services Association

Surname	Forename	Job title	Organisation
Guthrie	Sue	Commissioning Manger	Cruse Bereavement Care
Haigh	Andrew	Member	The Coroner's Society
Hartley	Jonathan	Author of 2001 standards	Cancer Counselling Trust, ABSCO
Henry	Claire	National Programme Director	National End of Life Care Programme
Herbert	Judith	Policy Lead - End of Life Care	Department of Health
Hindmarch	Jean	Projects Director	Help the Hospices
Hill	Sarah	Service and Development Manager	Cruse Bereavement Care
Hodge	Rachel	Transplant Coordinator	Organ Donation and Transplant
Hollick	Karen	Experienced Service User and Advisor	
Houghton	Jane	Practice and Service Development Manager	Together for Short Lives
Jones	Bob	Bereavement Network Manager	Care for the Family
Judge-Kronis	Lydia	Mortuary Manager Great Ormond Street	Association of Anatomical Pathology Technology
Kelly	Irene	Vice Chair	Cruse Bereavement Care
Kirk	Penny	EOLC Programme Manager	Yorkshire Cancer Network
Lawton	Rob	Senior Officer, Bereavement Services	Wolverhampton City Council
Lewis-Cordwell	Wendy	Bereavement Care Development	Bereavement Services Association
Lindsey	Katie	Project Manager	NEoLC Programme
Lymn Rose	Nigel	President	NAFD
Machin	Linda	Lecturer	Lancashire University
McKeeman	Carole	Trust Bereavement Cordinator	Western Health and Social Care Trust
McSherry	Wilf	Professor	National Bereavement Alliance Member
Molina	Louise	Project/Interim Manager	Projex Health Ltd
Morrison	Keith	Chaplain	Addenbrookes
Murray-Parkes	Colin	Life President	Cruse Bereavement Care
Penny	Alison	Coodinator	Childhood Bereavement Network

Surname	Forename	Job title	Organisation
O'Leary	Ruth	Lead Nurse for Bereavement and Chaplaincy	University Hospitals Birmingham - Queen Elizabeth Hospital
Relf	Marilyn	Founder	Bereavement Research Forum
Rolls	Liz	Honorary Research Fellow	University of Gloucestershire Bereavement Research Forum
Saville	Sue	Funeral Director	National Association of Funeral Directors
Shaw	Jo	Bereavement Officer	Hinchingbrooke NHS Trust
Smith	Pauline	EOL and Dementia Lead	NHS West Midlands
Speed	Joanne	Chief Executive Officer	The Dove Service
Stubbs	Di	Network Development Officer	Childhood Bereavement Network
Thompson	Alison	CYP Service and Development Manager	Cruse Bereavement Care
Ursell	Frank	Chief Executive	Registered Nursing Homes Association
Wadey	Anne	Head of Bereavement Advice	Bereavement Advice Centre
Whitmore	David	Senior Clinical Advisor	London Ambulance Service
Winstanley	Emma	National Referral Centre Manager	NHSBT
The Bereaved Parents Support Organisations (BPSON)			
Norfolk Child Bereavement Strategic Partnership			

The Gold Standard Bereavement Project Steering Group Members are grateful to all those who contribute to the revision of the Standards.