# BCSS

## **Bereavement Care Service Standards**





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## National Bereavement

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.

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## Foreword

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

## 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 the 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:** are 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 nondiscriminatory and delivered without prejudice, recognising and responding to personal beliefs and individual situations including (but not exclusive to) age, culture, disability, gender, sexuality, race, religion and spirituality (Equality Act 2010).
- Quality: services should ensure that all those delivering support to bereaved people, whether in a paid or voluntary capacity, have the skills, knowledge, training, supervision and support relevant to their role, and that services work to improve what they offer.
- Safety: services should have robust processes for recruitment, including appropriate levels of clearance with the Disclosure and Barring Service and ongoing staff/volunteer development. There needs to be due regard to safe and ethical practice in order to protect bereaved people and those who work with them. The necessary processes for safeguarding must be in place and accountability evidenced through an audit trail.

#### **About the Standards**

The framework used to structure these Standards falls under seven 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 recognises 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.

## The Standards

## 1

#### Planning

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

#### Levels

#### $(\mathbf{l})$

Service is planned in response to identified need.



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 evidencebased practice.

## 2

#### Awareness and Access

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

#### Levels

#### $(\mathbf{l})$

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.

## 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.

#### .evels

#### $(\mathbf{1})$

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.

## 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.

#### Levels

### 1

Service staff/volunteers have ready access to timely ad hoc support.



Staff/volunteers have access to and attend regular structured support activities.

#### 3 Service s

Service staff/volunteers have access to regular supervision as a requirement of continued practice.

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### 5

#### Education and Training

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

#### Levels

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.

## 6

#### Resources

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

#### Levels

#### $(\mathbf{l})$

Service provides designated areas and resources for providing bereavement care.

#### (2)

Service provides access to communication support, e.g. interpreters.

#### (3)

Service provides appropriate ratios of staff/ volunteers to bereaved people, especially in relation to vulnerable and young people.

### 7

#### Monitoring and Evaluation

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

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#### (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 context of the Standards

The Standards fit within a framework of service development. They are just part of a process which encompasses four 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.

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.

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.

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.

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.

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 Programme for Adults.

Bereavement Care Services: A synthesis of the literature. Department of Health. University of Nottingham. Shaping Bereavement Care was published in Scotland. This identifies basic principles that should guide the provision of bereavement care services.

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 standardised template for the last care provided to those who have died and their carers.

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.

## List of consultees

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

#### Nikki Archer

Supportive Care Manager Association of Bereavement Service Co-ordinators in Hospice & Palliative Care

John Birrell Convenor Scottish Grief and Bereavement Hub

#### Tanya Brocklehurst

*Clinical Bereavement Coordinator* The Hospice of St.Francis and Mount Vernon Cancer Centre

#### Jo Charlton

Bereavement Care Coordinator Bereavement Services Association

Simon Chapman Director of Public and Parliamentary Engagement National Council for Palliative Care

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Helen Dowdeswell Commissioning Manager Cruse Bereavement Care

Yunus Dudhwala Head of Chaplaincy and Bereavement Services Newham University Hospital NHS Trust

**Georgia Elms** *Chairman* The WAY Foundation (Way Widowed and Young)

Alice Fuller Policy and Parliamentary Affairs Office National Council for Palliative Care

Ishbell Gall Chair Association of Anatomical Pathology Technology Barchester Healthcare

**Elizabeth Gallacher** *Care Specialist* Bereavement Services Alliance member

Sam Goss Mortuary Manager Salisbury NHS Foundation Trust Association of Anatomical Pathology Technology

Kathryn Griffin Bereavement Service Manager Bereavement Services Association **Sue Guthrie** *Commissioning Manager* Cruse Bereavement Care

Andrew Haigh Member The Coroner's Society

Jonathan Hartley Author of 2001 Standards Cancer Counselling Trust, ABSCO

**Claire Henry** National Programme Director National End of Life Care Programme

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Jean Hindmarch Projects Director Help the Hospices

Sarah Hill Service & Development Manager Cruse Bereavement Care

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Karen Hollick Experienced Service User and Advisor

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Katie Lindsey Project Manager NEoLC Programme

Nigel Lymn Rose Past President NAFD

Linda Machin Lecturer Lancashire University

**Carole McKeeman** *Trust Bereavement Co-ordinator* Western Health and Social Care Trust

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Keith Morrison Chaplain Addenbrookes

**Colin Murray Parkes** *Life President* Cruse Bereavement Care

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**Marilyn Relf** *Founder* Bereavement Research Forum

Liz Rolls Honorary Research Fellow University of Gloucestershire, Bereavement Research Forum

Sue Saville Funeral Director National Association of Funeral Directors

**Jo Shaw** Bereavement Officer Hinchingbrooke NHS Trust

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**Di Stubbs** Network Development Officer Childhood Bereavement Network

Alison Thompson CYP Service and Development Manager Cruse Bereavement Care

Frank Ursell Chief Executive Registered Nursing Homes Association

Anne Wadey Head of Bereavement Advice Bereavement Advice Centre

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The Bereaved Parents Support Organisations (BPSON)

Norfolk Child Bereavement Strategic Partnership

## 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 and Co-Chair of the BSA

#### **Debbie Kerslake**

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Ann 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)

#### Yunus Dudwala

(Equalities Adviser) Head of Chaplaincy and Bereavement Services, Newham University Hospital NHS Trust

The Gold Standard Bereavement Project steering group members are grateful to all those who contributed to revision of the Standards.

These Standards were produced by:

Bereavement Services Association www.bsauk.org.uk

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