STANDARDS FOR BEREAVEMENT CARE

No. 2 of a series of information resources compiled on behalf of the Irish Hospice Foundation.

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This document is intended as a resource for those charged with developing bereavement services in palliative care in Ireland. Its primary aim is to disseminate current information. For more information contact the Irish Hospice Foundation, Morrison Chambers, 32 Nassau Street, Dublin 2, tel. 01- 679318; e-mail info@hospice-foundation.ie. See also www.hospice-foundation.ie
1 Standards for bereavement care

Bereavement and grief are natural processes and the majority of people find their own way through their loss. Nevertheless some people will experience difficulty in adapting and may benefit from the support of others outside of their extended family and friends. A small minority may benefit from professional assistance to help them cope. Just as death itself can be sudden or protracted, and as health professional involvement can vary, so too does the provision of bereavement care. Provision of bereavement care can take different forms, occur in varied contexts and be offered by a range of professionals through to volunteers.

The efficacy of grief support interventions is difficult to assess – in part because grief is an individual process reflecting past relationships, current support and practical problems; in part because of the range in organisation of bereavement services, including variation in the timing of invitations to support, the link to pre-death care, and provision of group support or individual support on a limited or open-ended basis.

Within the context of palliative care the care of bereaved individuals and families is a stated principle. A number of international organisations have set out to identify the underlying principles and more specific standards, which should guide the development of bereavement support, in general in the community and more specifically in the palliative care environment.

1.1 Why standards in bereavement support?

- Generally, professionals are reluctant to refer families to services of unknown quality. The standards allow a framework of the type of questions to ask of a bereavement service situated in the community.

- Where palliative care services are planning to develop bereavement support services, reference to existing standards provides a practical basis for planning the organisation of such a service

- The existence of explicit standards allows for evaluation – are goals being met, is a minimum standard operating

- The UK projects on standards for bereavement care aimed to provide a tool ‘to ensure that those who deliver support do so safely, ethically and appropriately’

- Reference to bereavement standards for bereavement care does not ‘compartmentalise’ or ‘fragment’ bereavement care. Those involved in the care of patients and family still have a role to play:

  ‘Bereavement sensitive practice’ is a concept that should extend to the organisation as a whole to promote a sensitive and timely response to the individual needs of bereaved people. The existence of a bereavement
• Bereavement standards are not overly rigid. They do not stipulate the exact shape and form of services, rather they often illustrate the practical means of achieving principles of good practice – e.g. of confidentiality.

In Ireland the extent to which hospice and palliative care services can currently provide comprehensive bereavement support is variable. This paper will describe some of the relevant standards for provision of bereavement support and reference the source documents for those who would like to obtain further information.

1.2 Principles underlying bereavement support

In developing standards several organisations’ first step has been to identify the principles which should underlie the provision of care. Two sets of principles are illustrated here – the UK principles for generic bereavement support and Palliative Care Australia’s principles derived through consensus among palliative care staff.

Palliative care services looking to develop their bereavement services and connections with local bereavement support agencies could begin by identifying the principles that will guide such services.

Standards for Bereavement Care in the UK, 2001

Providers of support to bereaved people should:

a) be responsive to the needs of each bereaved person.

b) acknowledge and affirm bereavement, and the pain of grief, as a natural part of human experience.

c) support each bereaved person in his/her ongoing adjustment to life without the deceased.

d) respect each bereaved person’s choices and variety of expressions of grief consistent with different patterns of belief, family, community, culture and religion.

e) be demonstrably non-discriminatory and deliver without prejudice, so that wherever practicable the bereaved person is able to access appropriate support regardless of their age, colour, disability, ethnic or national origin, financial circumstances, gender, geographical location, health status, language, marital status, race, religion, or sexual orientation.
f) respect the confidentiality and privacy of each bereaved person and information shared by them.

g) minimise the risk of mental and physical complications that can be associated with bereavement.

h) ensure each bereaved person is aware of the support available to them by proactively disseminating information about their services to potential beneficiaries, including the bereaved, local agencies and health and social care professionals.

i) be clear about the boundaries of the support offered to each bereaved person and offer information on services available elsewhere to meet the needs which are beyond their services’ scope and abilities.

j) ensure that volunteers and paid staff are educated and trained appropriately to consolidate, develop, maintain and enhance their knowledge and skills in bereavement support, loss and grief.

k) ensure that volunteers and paid staff receive appropriate levels of supervision and support, relevant to their involvement in working with bereaved people.

l) encourage reflective practice to validate and improve on current practice.

m) involve all stakeholders in planning, design, development and delivery of services

n) collect data to monitor and evaluate outcomes leading to effective change, including feedback from clients, volunteers and paid staff, referral agencies and supervisors.

o) be organisationally open and accountable.

Principles for provision of bereavement support by palliative care services in Australia

Core Value

The provision of hospice and palliative care services includes grief and bereavement support for the patient, family and other carers during the life of the patient and continuing after death.

Aims

- Services aim to support the bereaved as they adjust to life without the deceased.
- Services aim to assist the bereaved through the normal process of grief.
- Services aim to reduce the risk of physical and mental complications associated with grief.
Structure

- Bereavement support services are offered to the families and carers of all palliative care patients.
- Services are provided by staff and volunteers who have received specific education in bereavement support, grief and loss.

Processes

- Services will ensure volunteers and staff involved in bereavement support receive ongoing education and training.
- Services will provide supervision and support activities for volunteers and staff involved in bereavement support.
- Services will ensure that people with, or at risk of, complicated grief reactions are offered bereavement counselling or referred to specialist bereavement counsellors for follow-up.
- Services will use a risk assessment tool to identify people with, or at risk of, complicated grief reactions.
- Services will begin assessing families and carers for risk as soon as possible after first contact is made with the patient.
- Services will ensure that the bereaved are informed about services available to them including notices regarding events such as memorial services and group meetings.
- Services will provide education about loss and grief to the community.
- Services will collect data to evaluate outcomes.
- Services will collect data for planning/budget purposes.

2. Standards for bereavement support

While principles provide the value framework for bereavement care, standards offer more practical guidelines for the development and assessment of bereavement services. Again, standards for general bereavement care (UK) and standards specific to palliative care (Victoria, Australia) will be given as examples.

2.2 The United Kingdom

The UK project for Bereavement Care Standards involved wide consultation with providers and users of services. Ten standards were developed. Each standard is broken down in detail in terms of structure, process, outcome and monitoring. The standards are as follows:

- Confidentiality
- Equal Opportunities
• Health and Safety (healthy, safe and an accessible environment for bereaved people and providers)
• Record keeping and administration
• Selection, recruitment and training of volunteers
• Statement of purpose (purpose, how this is delivered and who can use the service)
• Support and supervision
• Training

2.2 Australia

The Centre for Grief Education published standards specific to the provision of bereavement support in palliative care. The standards were derived with reference to Palliative Care Australia’s principles (described above) and also relative to a review on risk assessment. An abbreviated version of the twelve standards is duplicated below:

**Standard 1: Access**
The bereavement support program is designed to ensure the community of bereaved clients has access to services regardless of age, gender, culture, sexual orientation, socio-economic status, religious or spiritual beliefs, physical or other disability, or ability to pay.

**Standard 2: Coordination of the bereavement support program**
The bereavement support program provides coordinated services to individuals/families

**Standard 3: Staff Education**
Education is available to enable staff (paid and unpaid) to develop, maintain and enhance their bereavement support skills.

**Standard 4: Staff Support**
The bereavement support program recognizes and responds to the impact on staff of providing care to the bereaved.

**Standard 5: Service provision**
The bereavement support program provides a range of support services that are sensitive and appropriate to a person’s needs-in particular life stage and style of grieving.

**Standard 6: Bereavement Risk Assessment**
A bereavement risk assessment is routinely undertaken as part of the initial and ongoing individual/family assessments

**Standard 7: Referral to specialist services**
Where identified need exceeds the available capacity of the bereavement support program, the individual/family are referred to external specialist services

**Standard 8: Community Education and Promotion**
The importance of promoting community awareness of bereavement issues and acceptance of the bereaved is recognized and acted upon.
Standard 9: Privacy and confidentiality
The bereavement support program ensures the privacy and confidentiality of its clients.

Standard 10: Integration within the health and support system
The bereavement support program is part of a general health and support system working to promote the health and well being of bereaved clients and the wider community.

Standard 11: Resource allocation
Resources are allocated in a systematic manner that allows the bereavement support program to respond to the changing needs of clients and staff.

Standard 12: Research, program evaluation and quality improvement
The bereavement support program is committed to improve outcomes for bereaved clients through research, program evaluation and quality improvement.

Conclusion
This paper outlines some of the work to date on standards in the provision of bereavement support. It identifies the underlying principles gleaned through consensus processes in other countries. References are given which are specific to bereavement support in palliative care.

Bibliography/websites


Palliative Care Australia (1998): Principles for the provision of bereavement support by palliative care services in Australia http://www.pallcare.org.au/