

*ABC of palliative care***Bereavement**

Frances Sheldon

Bereavement is a universal human experience and potentially dangerous to health. It is associated with a high mortality, and up to a third of bereaved people develop a depressive illness. Help targeted at those most at risk has been shown to be effective and to make the most efficient use of scarce resources. When a death is anticipated, preparation for bereavement can be made, and this can also improve outcome.

The process of grief

Grief has been described in terms of stages or tasks, but all writers emphasise that it is not a neat and ordered process but rather overlapping phases of a mixture of emotions and responses.

A sense of shock, disbelief, and denial may occur even when death is expected, but these are likely to last longer and be more intense with an unexpected death.

During the acute distress that usually follows, bereaved people often experience physical symptoms, which may be due to anxiety or may mimic the symptoms of the deceased. For some, there may be questioning of previously deeply held beliefs, while others find great support from their faith, the rituals associated with it, and the social contact with others of a like mind, which religious affiliation often brings.

In time the great majority of bereaved people gradually re-engage with life and adjust to their situation. However, family events and anniversaries may sometimes reawaken painful memories and feelings—in this sense grief never really ends.

A crucial factor is the meaning of the loss for the bereaved person, and the painful search for understanding of why the death occurred is another common feature of bereavement. Throughout the period of bereavement bereaved people may oscillate between concentrating on the pain of the loss and distracting themselves through work or planning for the future.

Factors associated with poor outcome

Research has identified several factors that increase the risk of poor outcome. The relationship with the deceased person is very important: an ambivalent or dependent relationship is linked with higher distress, no matter whether it was the person who died or the person bereaved who was overtly dependent on the other.

Elderly widowers in Western societies have a particularly high risk of dying in the first six months after their partner's death, and suicide risk is markedly increased in this group. Widows tend to report more symptoms in bereavement than widowers—younger widows acknowledge more psychological difficulties, older widows report more physical symptoms.

The death of a child is regarded by Western societies as one of the most painful bereavements because it is now so rare. There is a high risk of marital difficulty and breakdown for parents after a child's death.

Generally, sudden and unexpected death is linked with long lasting and high levels of distress, especially if it is associated with violence, suicide, or substance misuse. Cardiovascular disease is the most common cause of sudden death, but in this case a modifying factor may be the timeliness of the death. The



"The deathbed of Madame Bovary" by Albert-Auguste Fourie (b 1854)

Stages of grief**Initial shock**

Common emotions and experiences—Numbness, disbelief, relief

Task—Accept the reality of the loss

Pangs of grief

Common emotions and experiences—Sadness, anger, guilt, feelings of vulnerability and anxiety, regret, insomnia, social withdrawal, transient auditory and visual hallucinations of the dead person, restlessness, searching behaviour

Task—Experience the pain of grief

Despair

Common emotions and experiences—Loss of meaning and direction in life

Task—Adjust to an environment in which the deceased is missing

Adjustment

Common emotions and experiences—Develop new relationships or interests

Task—Emotionally relocate the deceased to an important but not central place in bereaved person's life and move on

Risk factors for poor outcome of bereavement**Predisposing factors**

- Ambivalent or dependent relationship
- Multiple prior bereavements
- Previous mental illness, especially depression
- Low self esteem of bereaved person

Around the time of death

- Sudden and unexpected death
- Untimely death of young person
- Preparation for the death
- Stigmatised deaths—Such as AIDS, suicide
- Culpable deaths
- Sex of bereaved person—Elderly male widower
- Caring for deceased person for over 6 months
- Inability to carry out valued religious rituals

After the death

- Level of perceived social support
- Lack of opportunities for new interests
- Stress from other life crises

sudden death of an elderly person who has lived a full life is generally more acceptable than the death of a young person in a road traffic accident.

In palliative care few deaths are sudden or unexpected to professionals, but it is important to remember that bereaved friends and relatives may have a different view. For informal carers, the strain of caring for a terminally ill person for longer than six months is associated with an increased risk of poor outcome.

People from minority cultural or ethnic groups may experience problems if, at the time of a death, they are not able to follow the rituals and customs they think appropriate.

Deaths carrying a stigma, such as deaths from AIDS or suicide, or deaths for which the bereaved carries some responsibility also bring a higher risk of poor outcome.

After the death, bereaved people who perceive their social support as inadequate are more at risk. Opportunities for developing new interests and relationships may not be available to elderly bereaved people, who may be experiencing reduced mobility or sensory losses because of their own state of health. On the other hand, elderly people may have a more accepting attitude to death because of their experience, while younger people, with higher expectations of the possibility of cure, struggle with its inevitability.

Assessing complicated grief

Since grief and its expression are so much influenced by the society in which a bereaved person lives, and by attitudes and expectations in the immediate family, assessing whether grief is pathological or abnormal is complex. It must take into account several elements.

Intensity and duration of feelings and behaviour—A widow who cries every day about the death of her husband in the first few weeks after his death is within the normal range: if she is doing so 12 months later there is cause for concern. Intense pining, self reproach, and anger are danger signs, as is prolonged withdrawal from social contact. Failure to show any signs of grief is also an indicator, but some people do recover in a few days, especially if they are well prepared for the death.

Culturally determined mourning practices—A mother who maintains the room of her 11 year old son, who died four years ago, as a shrine would be unusual in Britain, but a widow in Japan might talk to her dead husband for the rest of her life as she makes offerings at the household shrine.

Any risk factors likely to make bereavement longer lasting or more deeply challenging.

Bereaved person's personality—Does the person normally express emotion dramatically or is he or she normally self contained and private?

Vulnerable groups

Children

Well meaning adults often wish to protect children from painful events and information during a death in the family but, by doing so, may make children feel the pain of being excluded from events that are very important to them. Children begin to develop an understanding of some aspects of death and bereavement as early as 2 or 3 years. By the age of 5, over half of children have full understanding, and virtually all children will by the age of 8. How early a child develops such understanding depends primarily on whether adults have given truthful and sensitive explanations of any experience of death that the child may have had, and only secondarily on the level of cognitive development.



Shock and disbelief are more intense after an unexpected and untimely death of a young person



Rituals and public solemnisation of grief are important

How to help in complicated grief

Avoided or repressed grief—Guided mourning that encourages the approach to avoided cues in relation to the dead person

Inability to detach from the dead person, often linked to excessive guilt or self reproach—Saying "goodbye" to the dead person through writing a letter or having an imaginary conversation with the person supported by a therapist

Chronic grief or avoidance of a new lifestyle—Setting small but progressive goals for change in the context of a therapeutic relationship

Grief after traumatic unexpected death—Consider treatment for post-traumatic stress disorder before treatment for grief reaction



Adults often try to protect children from painful events, including attendance at funerals

When a death is about to occur or has occurred, it is important to discuss with parents what experience of death their children have and what they have been told about the current situation, and to encourage the children to ask any questions. Parents are the best people to talk to their children, but they may need support and advice from professionals. Storybooks and workbooks on death and bereavement have been produced for children.

Parents may be preoccupied with the practical difficulties of caring for someone who is dying or overwhelmed with their own grief. In this case it may be useful to involve concerned family friends or teachers. For adolescents struggling to develop their individuality and independence, their peer group may be a helpful resource, particularly if it includes someone who has also experienced the death of a family member.

Confused elderly people and those with learning disabilities

The needs of these groups for help in dealing with bereavement have often been ignored. Repeated explanations and supported involvement in important events, such as the funeral and visiting the grave, have been shown to reduce the repetitious questions about the whereabouts of the dead person by confused elderly people or difficult and withdrawn behaviour in people with learning disabilities. This makes their continuing care less demanding for both family and professional carers.

What helps?

Identifying people potentially at risk in bereavement—Much pathology can be avoided by work before the death to minimise the effect of factors that increase risk of poor outcome.

Being present at the death, seeing the body afterwards, and attending the funeral or memorial service—These are helpful provided the bereaved person (including children) wishes to participate and is prepared for these events.

Providing information to bereaved people about the feelings they may have and about sources of voluntary support through leaflets or empathetic personal contact.

Counselling targeted at those in high risk categories, particularly those who perceive their social supports to be unhelpful. Counselling to unselected groups shows little benefit. Visits by trained bereavement volunteers have been shown to reduce use of general practitioners' services.

Opportunities to meet in bereavement groups, where people can safely test out the often disturbing feelings, questions, and thoughts that they have with others going through similar experiences.

There is no single intervention that meets the needs of all bereaved people, but there is an increasing range of resources for them to draw on. Most hospices offer a bereavement service to families with whom they are in contact. This may range from a telephone call or individual visits by volunteers to group meetings. Many areas have branches of the national self help organisations. In addition psychologists, community psychiatric nurses, and social workers with an interest in health care have the skills to work with bereaved people whose problems require more than the loving support of family and friends or the sharing of experiences with other bereaved people.

Books for children to read or use

- Couldrick A. *When your mum or dad has cancer*. Oxford: Sobell Publications, 1991
 - Heegard M. *When someone has a serious illness*. Minneapolis: Woodland Press, 1991 (workbook)
 - Heegard M. *When someone very special dies*. Minneapolis: Woodland Press, 1988 (workbook)
 - Mellonie B, Ingpen R. *Lifetimes*. Melbourne: Dragon's World, 1983
 - Stickney D. *Water bugs and dragonflies*. London: Mowbray, 1982
 - Varley S. *Badger's parting gifts*. London: Picture Lions, 1982
 - Williams G, Ross J. *When people die*. Midlothian: Macdonald Publishers, 1983 (for teenagers)
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Organisations for bereaved people

Compassionate Friends

- 53 North Street, Bristol BS53 1EN (tel 0117 966 5202)
- National organisation with local branches. Offers befriending to bereaved parents after loss of child of any age

Cruse Bereavement Care

- Cruse House, 126 Sheen Road, Richmond TW9 1UR (tel 0181 332 7227)
- National organisation with local branches. Offers counselling and befriending, home visits, and social meetings. Some specialist services

Jewish Bereavement Counselling Service

- PO Box 6748, London N3 3BX (tel 0181 349 0839)
- Counselling by trained volunteers. Telephone helpline

Lesbian and Gay Bereavement Project

- AIDS Education Unit, Vaughan M Williams Centre, Colindale Hospital, London NW9 5HG (tel 0181 200 0511)
- Advice, support, and counselling for bereaved gay men, lesbians, and their families and friends. Education. Telephone helpline (evenings)

National Association of Bereavement Services

- 20 Norton Folgate, London E1 6DB (tel 0171 247 0617)
- Referral agency. Publishes directory of bereavement and loss services. Support organisation for bereavement services

SANDS (Stillbirth and Neonatal Death Society)

- 28 Portland Place, London W1N 4DE (tel 0171 436 5881)
 - Support for parents after stillbirth or neonatal death
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