

Bereavement

Definition of Bereavement

The word *bereavement* comes from the Old English *berafian*, which means to rob, to plunder, or to dispossess. This implies that death deprives us of a continuing relationship with a loved one. In our society, the term *bereavement* refers to a separation or loss through death.

Bereavement reactions consist of the physiological, or behavioural responses to loss. Responses are individual and vary in intensity, duration and frequency. The occurrences of these reactions comprise the bereavement process, which can persist from weeks to years.

Definition of Grief

The word *grief* is derived from the Latin word *gravis*, which means heavy. The same word was later used by the French to convey that the spirits were heavy with sorrow. Grief is thought to be a normal reaction to loss. It was defined by Rando (1984) as a process of psychological, social and somatic reactions to the perception of loss.

Grief is a universal emotion; it is inescapable and undeniable. It knows no socioeconomic boundaries and shows no cultural preference. When faced with grief, many are surprised at how powerful and painful the feelings are. Grief can be compared to being mortally wounded or severely burned. As with those who have suffered burns, the healing process is long and painful and the scars remain.



BEREAVEMENT PROTOCOL



Following discussion in PHCT meeting, choose an appropriate card suitable for all cultures, religions, beliefs etc. insert an appropriate poem, prose or saying - usually non-denominational

Send card from the Practice immediately after the death of the loved one, if possible signed by those involved with the care of the patient. Include local support available as well as national groups e.g. CRUSE. (Could develop own leaflet)

Adopt/develop assessment tool for measuring those at risk

Discuss in PHCT meeting who would be the most appropriate person to visit the bereaved - possibly the one with most involvement

Do not leave arrangements to 'ring if needed' or 'pop in if you're passing'

Telephone to arrange a visit either pre or post funeral

Discuss and agree with carer a visit one month later

Discuss and agree with carer a visit three months later

Discuss and agree with carer a visit six months later

Discuss and agree with carer a visit nine months later

Discuss and agree with carer a visit a year later

Withdraw at any time that seems appropriate but during each visit assess for referral to a specialist team

Send anniversary card if Practice protocol

EXAMPLE OF BEREAVEMENT LETTER

PRACTICE HEADED PAPER

Dear relatives/friends of(patient's name)

The doctors, nurses and staff atPractice were very sorry to hear of your recent bereavement. We would like to offer our condolences.

We realise that this time may be very difficult for you. If you think we can help in any way please feel free to contact us. We enclose a leaflet about bereavement which you may find helpful. If you need some personal support your own GP or practice nurse, (district nurse) will be happy to see you.

With sincere sympathy,

On behalf of the doctors, nurses and staff.

RISK ASSESSMENT IN BEREAVEMENT

(Marilyn Relf)

A great deal of research has been carried out on what happens to people after a major loss. Bereavement:

- ❖ *Predisposes people to physical and mental health illness*
- ❖ *Precipitates illness and death*
- ❖ *Exacerbates existing illness*
- ❖ *Leads to, or exacerbates, health threatening behaviour such as smoking, drinking and drug use*
- ❖ *Results in an increased use in health services*
- ❖ *May lead to depression*

It is impossible to predict accurately how people will respond to bereavement. Grief:

- ❖ *May be immediate or may be delayed (timing)*
- ❖ *May be brief or may seem unending (duration)*
- ❖ *May be severe or may be mild (intensity)*

The following variables have been found to be significant in predicting how the person will respond to loss:

Mode of Death

- ❖ *Was it timely or untimely?*
- ❖ *Was it expected or unexpected?*
- ❖ *Was it unduly disturbing for the relatives or key carers?*

Deaths that are untimely, unexpected and/or unduly disturbing are likely to cause more severe and more prolonged grief. Note: The death of someone with terminal illness can still be unexpected.

Nature of the Relationship

- ❖ *How ambivalent is the relationship between key carer and patient?*
- ❖ *In any close relationship there is always a certain degree of ambivalence with positive and negative feelings co-existing*

In a highly ambivalent relationship where the positive and negative feelings co-exist in about equal proportion, there is going to be a more difficult grief reaction. Often this manifests as persistent feelings of guilt

- ❖ *How necessary was the deceased for the key carer's sense of well-being, self esteem or security?*

The more dependent the relationship the more all-pervading is the sense of loss.

Perceived Support

- ❖ *Is the carer able to share her feelings with family and friends?*
- ❖ *Does she feel supported or isolated in her loss?*

Anticipatory Grieving

- ❖ *Were the family and patient able to talk about the illness and make plans for the future before the patient died?*
- ❖ *Was the key carer able to share her feelings?*

Some denial is to be expected but if there is much denial then it may be hard to start sharing after the death.

If there is a lot of anger present, this is likely to persist and delay the process of grief.

Concurrent Life Events

- ❖ *How much stress is the key carer/family currently facing?*
 - ❖ *Financial difficulties*
 - ❖ *Menopause*
 - ❖ *Children leaving home*
 - ❖ *Unemployment*
 - ❖ *Retirement*
- ❖ *How many people are dependent on the key carer such as children or elderly relatives?*
- ❖ *Has the key carer time and space to grieve?*
- ❖ *How does she see these concurrent or recent life events impinging on themselves?*

Previous Losses

- ❖ *How has the person grieved for previous losses?*
- ❖ *Will the new loss uncover still unresolved previous loss?*

Medical History

- ❖ *Has the person a concurrent physical illness which is likely to be exacerbated by their loss?*
- ❖ *Has the key carer a history of alcoholism or drug abuse?*

The most positive factor in favour of a good outcome is the presence of a supportive family and/or friends who allow the bereaved person to express her grief and to talk unconditionally about her feelings for as long as she wants to.¹²

"The pain of grief cannot be avoided but it can be shared, and there is much truth in the old saying. "A trouble shared is a trouble halved". Family members and friends who are close to a bereaved person can often be of enormous help, just by allowing the bereaved person to grieve".

It isn't a matter of having a clever set of answers which will somehow take away the pain. A person's mere presence, showing care and concern and a willingness to be close, may be the most important help that a bereaved person will get.

If we don't mourn (grieve), sooner or later it catches up with us, and then it can be difficult to handle.³

The bereavement Support Service at Sobell House attempts to provide this function for those who do not have, or are unable to accept support from family and close friends.

**KIRKWOOD HOSPICE
VULNERABILITY QUESTIONNAIRE**

Please complete for each key person, using two columns if necessary. Please circle number (comment if necessary, overleaf).

- | | |
|--|---|
| <p>1. Person's relationship to the patient:</p> <p>Widow 5 Widower 5 Partner 5 Child under 15 5 Dependent adult child 3 Parents of adult child 5</p> <p>2. Has the patient got children living at home?</p> <p>Aged 0-5 5 Aged 6-12 2 Aged 13-16 4</p> <p>3. Is the main carer unusually dependent, clinging, insecure or sensitive to separation?</p> <p>Some 3 Much 5</p> <p>4. Unusually angry or bitter</p> <p>Some 3 Much 5</p> <p>5. Unusually self-reproachful or guilty</p> <p>Some 3 Much 5</p> <p>6. Is the family unable to share feelings or reluctant to face patient's illness?</p> <p>Some 2 Much 5</p> | <p>7. Is the main carer inclined to consume alcohol or other drugs? (including tranquillisers, anti-depressants etc)</p> <p>None or a little 0 Moderately 2 Heavily 5 Alcoholic or drug addict 10</p> <p>8. Available support: Does the main carer lack a caring family or does their family/friends inhibit the expression of grief?</p> <p>Some 2 Much 5</p> <p>9. Is the main carer facing a concurrent life crisis eg other losses, moving house financial difficulties, redundancy etc? (Please comment overleaf)</p> <p>Major 5 Minor 3</p> <p>10. Is the main carer suffering from:</p> <p>Minor nervous problems 5 Major nervous problems 10 Minor heart disease) including 5 Major heart disease) stroke 10 Threat of suicide in the past 5 Serious risk of/or attempted suicide in the past 10</p> <p>11. Is the main carer in need of bereavement support?</p> <p>Probably 5 Definitely 10</p> |
|--|---|

This form was completed by

Family Care Team use only

| | | |
|--------------|--------------------------|--------------------|
| | Decision | |
| Total | <input type="checkbox"/> | Low Risk/High Risk |
| Total | <input type="checkbox"/> | Low Risk/High Risk |
| GP contacted | <input type="checkbox"/> | YES/NO |

If score is above 18 - at High Risk

NOTES FOR NURSES MAKING TELEPHONE CALLS TO BEREAVED RELATIVES

SOME NORMAL GRIEF REACTIONS

- 1 Preoccupation with thoughts of the dead person leading to tearfulness and to initial insomnia.
- 2 Visual phenomena. Illusions of seeing the dead person and pseudo hallucination visual, auditory and physical.
- 3 Yearning
- 4 Anger
- 5 Guilt
- 6 Poor concentration
- 7 Indecision, restlessness
- 8 Forgetfulness
- 9 Fatigue
- 10 Searching - knowing that the person is dead but going hopefully to places where they would have been.

SOME FACTORS INCREASING THE RISK OF A DIFFICULT GRIEF

- 1 Sudden or unexpected death.
- 2 Multiple losses.
- 3 Over dependence on lost relative.
- 4 Lack of support.
- 5 Other life crises.
- 6 Existing mental illness, especially depression.
- 7 Carer not present at death
- 8 Or not peaceful.

CHECK LIST WHEN TELEPHONING BEREAVED RELATIVES

- 1 Sleep
- 2 Appetite (+ or -)
- 3 General health
- 4 Going out
- 5 Keeping in touch with family and friends
- 6 Feelings of excessive anger or guilt - do they need to be explored?

THE FOUR TASKS OF MOURNING

(WILLIAM WORDEN 1992)

TASK 1: To Accept the Reality of the Loss

This is the starting point for grief, the intellectual and emotional recognition of the loss by the loved one. Intellectual understanding of the loss tends to come first, and in normal grief quite quickly, the emotional acceptance being worked through alongside the next tasks.

TASK 2: To Work Through the Pain of Grief

Once the reality of the loss has been intellectually recognised, the pain of the grief begins to be felt. This normally involves a sometimes bewildering confusion of difficult emotions, which need to be "allowed" to be recognised and experienced fully.

TASK 3: Adjust to an Environment in Which the Deceased is Missing

Change is inevitable when a loss is suffered. The nature and degree of change will vary depending on the nature and closeness of the loss, but the task is always to accept the necessary changes and to find appropriate ways of successfully achieving them.

TASK 4: To Emotionally Relocate the Deceased and Move on With Life

This is the hard task of saying goodbye, of releasing the lost person or object and the emotional ties with them, so that life, activities, relationships and interests can go on. It is not necessary to forget, or to stop loving, but to let go and move on.

TEN WAYS TO HELP THE BEREAVED

*Source: Bereavement & Loss Training Manual
By Alice Goodall, Tim Drage and Gilhan Bell - Published Winslow Press*

1. By being there
2. By listening in an accepting and non-judgemental way
3. By showing that you are listening and that you understand something of what they are going through
4. By encouraging them to talk about the deceased
5. By tolerating silences
6. By being familiar with your own feelings about loss and grief
7. By offering reassurance
8. By not taking anger personally
9. By recognising that your feelings may reflect how they feel
10. By accepting that you cannot make them feel better

KEYS TO GOOD LISTENING

(Barbara Ward and Associates(1994) , Good Grief , 4th ed, Jessica Kingsley Publisher

Warmth and Caring - being concerned, accepting, friendly.

Empathy - trying to understand how it feels to be in someone else's shoes and showing that you want to understand.

Non-judgemental Acceptance - not being shocked or judging someone. Accepting the person and their feelings.

Respect - allowing someone the dignity of having the right to feel any emotion and the free choice to choose any action.

Genuineness - being real, not just someone 'playing' a role.

Limit Your Own Talking - you can't talk and listen at the same time.

Clarifying - if you don't understand something, or feel you may have missed a point, clear it up by asking a relevant question.

Summarising - periodically check back with the person that you have heard them correctly by summarising the main points of what has been said. You may wish to encourage them to do the summary.

Questions - always use open-ended questions, ie questions which cannot be answered by just 'yes' or 'no'. Be careful not to interrogate.

Don't Interrupt - a pause, even a long pause, doesn't mean the person has finished saying everything they want to say.

Turn Off Your Own Words - personal fears, worries, problems not connected with the person easily distract from what they are saying.

Listen For Feelings - don't just concentrate on the facts as these are often less important than the feelings.

Don't Assume or Jump to Conclusions - don't complete sentences for the person either verbally or in your mind.

Listen For Overtones - you can learn a great deal from the way the person says things and what they do not say.

Concentrate/Attention - focus your mind on what the person is saying. Practice shutting out distractions.

NORMAL PATTERNS OF GRIEF AND MOURNING
FOLLOWING BEREAVEMENT
(COLIN MURRAY PARKES)

| <u>TIME</u> | <u>FEELING</u> | <u>BEHAVIOUR</u> |
|-----------------|--|---|
| Death - 2 weeks | <u>Shock</u> | Tears Sobbing Shivering Severe bodily & mental pain Deep sighing |
| | <u>Numbness</u> Isolation Depersonalisation | Indecision Irrational behaviour Withdrawal Clinging |
| | <u>Denial</u> | Constant Reminiscing Hallucinations Expects return |
| 1-3 Months | <u>Yearning</u> Acute Emotional Pain | Sobbing Pining Symptoms Illness Nightmares Disturbed Sleep Fatigue Lack Concentration Aimless Activity Idealisation of Deceased |
| | <u>Searching</u> Frustration | Restlessness Seeking Out Symbolic Child Regression |
| | <u>Anxiety</u> Insecurity Fear Dependency | Stays at Home Familiar Objects No Risks |

| <u>TIME</u> | <u>FEELING</u> | <u>BEHAVIOUR</u> |
|--------------------|--|--|
| 1-3 Months (Cont.) | <u>Anger</u> Jealousy Resentment | Irritability Why me? Misplaced anger |
| | <u>Guilt</u> Self Blame Religious Doubt - Guilt | |
| | <u>Loneliness</u> Rejection | |
| 8-9 Months | <u>Depression</u> Psychodynamic Components Present - Existing Personality Problems | |
| | <u>Apathy</u> Repress Anger No Feeling Don't Care Loss Identity | Lack of Will Neglect Aggressive |
| | <u>Mitigation</u> Joy at Good Memories | Making Sense of Grief Saying Goodbye |
| | <u>Stigma</u> Isolated | Loss Friends Avoid Couples |
| 1-3 Years | <u>Acceptance</u> Settled Deeper Maturity Solitude is Productive Freedom Positive Outlook Enjoyment | New hobbies Interest, friends Relationships Restructuring Talks happily about deceased Laughing |

DEPRESSION MAY CONTINUE IN OLDER PEOPLE

HOW TO HELP SOMEONE WHO IS SUFFERING FROM LOSS

DO let your genuine concern and caring show.

DO be available ... to listen or to help with whatever else seems needed at the time.

DO say you are sorry about what happened and about their pain.

DO allow them to express as much unhappiness as they are feeling at the moment and are willing to share.

DO encourage them to be patient with themselves, not to expect too much of themselves and not to impose any "shoulds" on themselves.

DO allow them to talk about their loss as much and as often as they want to.

DO talk about the special, endearing qualities of what they've lost.

DO reassure them that they did everything that they could.

DON'T let your own sense of helplessness keep you from reaching out.

DON'T avoid them because you are uncomfortable (being avoided by friends adds pain to an already painful experience).

DON'T say how you know how they feel. (Unless you've experienced their loss yourself you probably don't know how they feel.)

DON'T say "you ought to be feeling better by now" or anything else which implies a judgement about their feelings.

DON'T tell them what they should feel or do.

DON'T change the subject when they mention their loss.

DON'T avoid mentioning their loss out of fear of reminding them of their pain (they haven't forgotten it).

DON'T try to find something positive (e.g. a moral lesson, closer family ties, etc.) about the loss.

DON'T point out at least they have their other ...

DON'T say they can always have another ...

DON'T suggest that they should be grateful for their ...

DON'T make any comments which in any way suggest that their loss was their fault (there will be enough feelings of doubt and guilt without any help from their friends).

(From: "Good Grief. Exploring Feelings, Loss and Death with Over Elevens and Adults" by Barbara Ward and Associates. Jessica Kingsley Publishers, 1993)

READING LIST – BEREAVEMENT

Birtwistle J, Payne S, Smith P, Kendrick T.(2002) The role of the district nurse in bereavement support. *Journal of Advanced Nursing*, 38(5), p 467-478

Bowlby J, (1980) *Attachment and Loss Vol 1*, Penguin, Harmondworth

Charlton R, Dolman E, (1995) Bereavement: a protocol in primary care. *British Journal General Practice*, 45; p427-30

Kubler-Ross E, (1969) *On Death and Dying*. Tavistock Publications, London

McCorkle R, Robinson L et al, (1998) The effects of home nursing care for patients during terminal illness on the bereaved's psychological distress. *Nursing Research*. Jan-Feb; 47 p2-10

Parkes CM, (1996) *Bereavement: studies of grief in adult life*. 3rd Ed, Tavistock Publication, London

Payne S, (1994) The assessment of need for bereavement follow-up in palliative and hospice care. *Palliative Medicine* 8, p291-297

Payne S (2001) Bereavement support: something for everyone? Editorial *International Journal of Palliative Nursing* 7,3

Payne S (1999) *Loss and Bereavement*. Open University Press

Sheldon Frances, (1998) ABC of Palliative Care: Bereavement, *BMJ* 316: P456-458

Stoebe M Stroebe W Hansson R, (1999) *Handbook of bereavement: theory, research and intervention*. Cambridge University Press

Thomas K, (2003) *Care of the Dying at Home*. Radcliffe Press

Worden W, (1983) *Grief Counselling and Grief Therapy*. Routledge, London