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Death, dying and bereavement

- ATTACHMENT, a normal social process, is eventually broken either temporarily in SEPARATION or permanently in LOSS, as occurs at death.
- A dying patient typically passes through five successive stages, DENIAL AND ISOLATION, ANGER, BARGAINING, DEPRESSION and ACCEPTANCE.
- GRIEF, the psychological response to BEREAVEMENT, is a process with its own successive stages of DENIAL, PINING, DEPRESSION and finally ACCEPTANCE.
- Bereavement is highly stressful and is associated with impaired immune functioning and a raised mortality, particularly from cardiovascular disease.
- Grief occurs after all forms of loss, not only those involving death, and takes similar if less extreme forms in all cases.

Death is a normal part of life and its inevitable outcome. Ultimately we must all accept the inexorable demise of ourselves and those around us. Necessarily, it will be upsetting and unpleasant, and neither intellectual detachment nor analysis can make it less so. ATTACHMENT is the mortar that binds together our social system (see Chapter 10). Although attachment is principally to other individuals, parents, siblings, family, spouse, children, and friends, attachment can also be to pets, objects such as car, house or garden, or even to abstract ideas. Our attachment binds us to them, and with other people that attachment is reciprocated, strengthening the relationship. Attachments eventually are broken, either temporarily in SEPARATION, or permanently in LOSS. The most traumatic loss is DEATH, although similar processes occur, to greater or lesser degree, after job loss, exam failure, divorce, limb amputation, bankruptcy, rape or other abuse. A loved object disappears from the person's life. For the dying person that loved object is life itself, and the psychological process of dying is similar to bereavement.

BEREAVEMENT, loss of a loved object, and GRIEF, the psychological condition associated with that loss, are not states, or emotions, but are PROCESSES, with a natural evolutionary sequence to be worked through. As C S Lewis (1893–1963) put it in *A grief observed*, a moving account of his own responses after the loss of his wife:

> '[the book] turns out to have been based on a misunderstanding. I thought I could describe a *state*; make a map of sorrow. Sorrow, however, turns out to be not a state but a process. It needs not a map but a history . . . '.

Bereavement and grief require the cognitive and emotional re-working of memories, and the comprehension of a future without the lost object and its many concomitants (perhaps loss of income, interests, and friends in the case of a spouse). To quote C S Lewis once more,

> '. . . grief feels like suspense . . . because of the frustration of so many impulses that had become habitual. Thought after thought, feeling after feeling, had H [his wife] for their object. Now their target is gone. I keep on through habit fitting an arrow to the string; then I remember and have to lay down the bow. So many roads lead thought to H. I set out on one of them. But now there's an impassable frontier-post across it. So many roads once; now so many *culs de sac*'.

Bereavement is also a *social* process, with death registration, funeral service, and burial or cremation representing the formal, outward acts of MOURNING, which help the bereaved to adjust to loss, and to accept movement into a new stage of life, with a different social role, as from wife to widow. Mourning acts as an anthropological RITE OF PASSAGE, helping the bereaved individual in the transition, and proclaiming it publicly.

DEATH AND DYING. Death comes in many ways. For some it is sudden, clean, immediate and unexpected; for others it is slow, drawn out, and long anticipated by patient, relatives, doctors and nurses, and it needs to be coped with. Elizabeth Kubler-Ross describes five stages in accepting one's own death:

i. DENIAL AND ISOLATION. Ego defence mechanisms reject the diagnosis and its implications. The patient may become isolated from friends, relatives and carers.

ii. ANGER. The patient is angry with staff and relatives, envies others who will live, resents their own suffering, and looks for explanations, trying to attribute blame for the disease's cause. The anger often results in accusations of incompetence by doctors, who should realize the psychological basis for such charges, and that they are not genuine criticisms of the standard of care. An overly officious defence of medical practice only makes things worse for all concerned; instead sympathy and compassion are required.

iii. BARGAINING. Patients bargain with carers, perhaps offering money in the hope of improved care and a greater likelihood of survival.

iv. DEPRESSION. As death becomes foreseeable, patients become depressed and tearful, weeping not only for their own loss, but for the future suffering of those around them. The temptation to provide

false encouragement and assurances of recovery should be avoided, and instead the patient helped to work through the process, with the assistance of those around them.

v. ACCEPTANCE. The final stage when the patient accepts the inevitable, becomes resigned and passive, and often becomes detached emotionally from those around them.

Dying patients present many problems, some purely medical, as in the prescription of adequate quantities of analgesics to alleviate suffering. Other problems are personal for the doctor as dying patients often threaten one's own sense of well-being: death can wrongly be seen as a professional failure; it can upset directly if a close relationship has been formed; and it can be a chilling reminder of one's own mortality, for as John Donne said, 'No man is an island... any man's death diminishes me, because I am involved in mankind'. Ego defence mechanisms may make the doctor cultivate a professional detachment, or a cynical indifference to the problems of the dying, redoubling efforts for the treatable, and even denying the possibility of death in a patient. Such behaviours diminish the humanity of both doctor and patient, for death is both natural and inevitable, and should be seen as a normal part of caring. Although difficult at first for doctors, appropriate care of the dying can be very satisfying, and almost paradoxically, can itself be life-enhancing, increasing one's awareness of the good things that life has to offer.

The five stages of Kubler-Ross assume the patient knows their illness is terminal. Doctors often prefer not to break bad news, choosing to deceive rather than carry out the disagreeable and stressful task of telling the prognosis, and also fearing that the patient 'doesn't really want to know', and that induced feelings of hopelessness will produce a worse prognosis. Doctors can also be under pressure from relatives not to tell the patient, so that relatives themselves can avoid similar pressures. When well, 90% of the population say they want to be told if they are terminally ill (as do almost 100% of medical students and doctors); by contrast, during the 1960s, 90% of doctors thought patients *shouldn't* be told when terminally ill. Since then practice has changed, and many more patients are now told their diagnosis. Even if not told, most patients have a shrewd idea of their prognosis, and doctors and patients may engage in elaborate play-acting, each side pretending the other 'doesn't know that they know...'. Patients are very sensitive to social cues, particularly non-verbal, such as lack of eye-contact, shorter visits on ward rounds, evasive answers, false bonhomie, etc., and rapidly make an appropriate diagnosis for themselves. Perhaps the safest rule is to tell the truth, particularly if asked a straight, direct question ('Am I going to die?'), and only if certain that the patient is repressing, denying, or is asking for false reassurance, should one withhold the truth. Whatever the patient is

told, do record it in the notes, so other carers know the situation, avoiding embarrassing and unnecessary contradictions.

Most people are inexperienced or uncertain when discussing death and illness, and avoid it if possible. One survey found that only a third of married couples in which a member's imminent death was known to both partners had actually discussed that death together. Those couples had found warmth and reassurance from sharing, and found it had assisted both of them, whereas those who did not talk subsequently had regrets. The doctor's role is to facilitate such sharing. It is not easy in a general hospital ward, but far easier in a HOSPICE, a hospital specializing in terminal or CONTINUING CARE, where experience helps not only with physical caring, but with open psychological caring, both of patient and relatives.

Ultimately the doctor must realize that little positive can be done to avert psychological suffering, for in part it is inevitable; however, many actions of omission and commission can exacerbate the suffering of patients and relatives. If in doubt, a useful rule of thumb, as in all psychological care, is to place yourself in the position of the patient or relative and ask what *you* would want; for beyond doubt you will be in a similar position one day.

BEREAVEMENT AND GRIEF. Bereavement is a process with a succession of stages which have to be worked through. As Gorer has pointed out, '[it is not] a weakness, a self-indulgence, a reprehensible bad habit, [but is] instead a psychological necessity'. An important part of one's life has been removed, and this requires a substantial cognitive reordering. The future has changed irrevocably, and many of the presumptions of the present have become the past. Memories, often of a life-time spent together, can no longer be shared, and must now be relabelled as referring only to the past and not to the future. Life itself will indeed change, because bereavement not only entails loss, but also deprivation of companionship, security, shared responsibilities, a sexual partner, a confidante, income, a specific role in life, and a particular future. This rethinking and readjustment is the process that Freud called the 'grief-work'. An empty space has appeared in our view of the world which must be filled, and the emotions which would have been discharged onto that object have to be discharged onto other objects. Nevertheless, as Freud said, 'no matter what may fill the gap... it remains something else. And actually this is how it should be. It is the only way of perpetuating that love which we do not want to relinquish'.

As with dying, bereavement passes through a series of successive stages, commencing with DENIAL, often accompanied by PSYCHIC NUMBNESS in which there is a sense of unreality and lack of acceptance of the death. This stage can often be helped through if relatives can view the dead body, particularly if it appears calm and at rest. Death without a body, as in loss at sea, or in war, is particularly difficult to

ıourn appropriately, and leads to subsequent problems. That is also ·ue with death or stillbirth of infants, where if mothers can hold ıeir baby, and grieve for it openly, then adjustment occurs more ısily. By contrast, viewing of a mutilated body, as after death by ːcident, can produce a recurrent vision which is discrepant with ıemories of the living person, and can make grief more prolonged. he formal processes of a funeral, and burial or cremation, can also elp prevent denial.

The stage of denial can also be accompanied by ANGER; as with ying, this can be directed at hospital staff, in the form of accusations ·f incompetence or negligence, which should be treated not with ›verly defensive responses, but with a sympathetic understanding of he origins of these accusations. Parkes has called the second stage, vhich occurs after a few days or weeks of bereavement, PINING; there s a continuing process of SEARCHING for the loved one, frequently in ıcute episodes, the PANGS OF GRIEF being accompanied by severe anxiety, ›sychological pain, crying, and a sense of acute loss of the person. No one ever told me that grief felt so like fear... the same fluttering n the stomach, the same restlessness, the yawning. I keep on ːwallowing...', to quote C S Lewis once again. Initially frequent, hese pangs decline in frequency, but are often triggered by tiny events n life, a casual comment, the memory of a shared event, a photograph. This searching is in many ways the equivalent of a young child or ınimal restlessly looking for a lost parent, and in evolutionary terms nay be seen to be generally adaptive, although without hope of ːuccess in the case of death. Parkes has characterized the components ›f searching as:

1. Alarm, tension and a state of arousal.
2. Restless movement.
3. Preoccupation with thoughts of the lost person.
4. Development of a perceptual set for that person.
5. Loss of interest in personal appearance and other matters which normally occupy attention.
6. Direction of attention towards those parts of the environment in which the lost person is likely to be.
7. Calling for the lost person.

Notice that this is not the retarded picture associated with a depression (see Chapter 29), but is closer to the clinical picture of anxiety.

There is then often, but not always, a DEPRESSIVE PHASE, accompanied by a period of apathetic withdrawal, with a sense of hopelessness, of giving up, a preoccupation with thoughts of loss, a painful, repetitious recollection of the circumstances of the loss, and a sense of incomprehension of a world in which such events can be allowed to occur.

Bereavement can be a lengthy process, and ultimately is never truly complete, there always, as Freud suggested, being a part of our heart

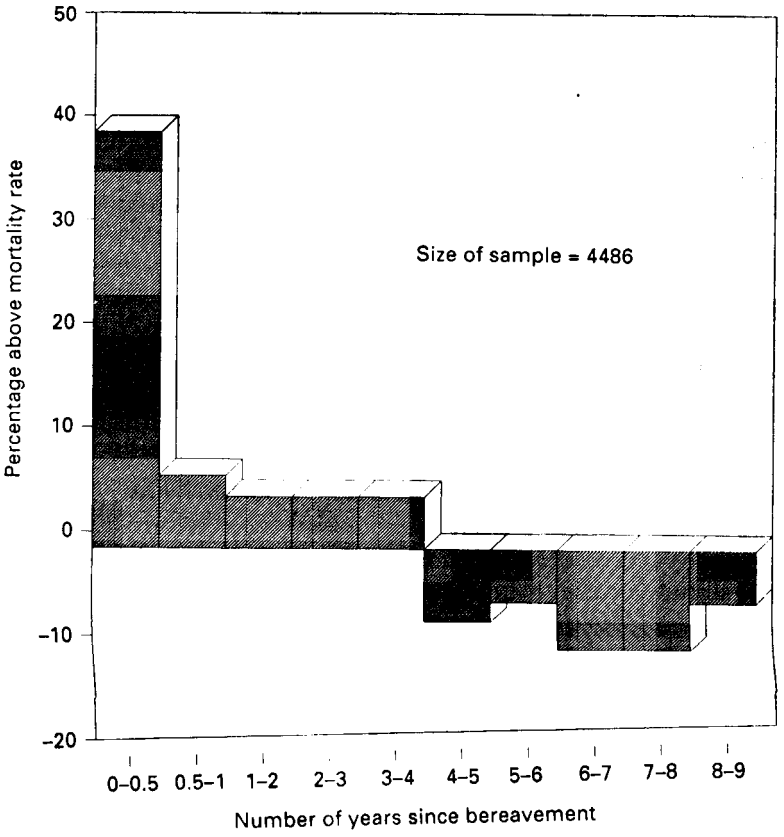

Fig. 18.1 The mortality of widowers aged over 54 compared with their expected mortality rate for men of the same age, for the first nine years after being widowed. Adapted from Parkes C M (1975), *Bereavement*, Harmondsworth, Penguin, 227.

which is forever elsewhere. Nevertheless normal life does resume again, although grief pangs can occur even years later. The 'normal' life will necessarily be different from that before loss, a reconstruction from the remnants of a previous stage of life. Several factors can prolong the grief reaction: AMBIVALENT RELATIONSHIPS (in which there is a mixture of love and hate towards the lost person) take longer to grieve adequately; sudden and unexpected deaths prolong grief, suggesting that in chronic illness much of the grief-work may be carried out in anticipation; and grief lasts longer in the absence of *social support* from friends or relations, or of other interests in life such as a job, or of opportunities for developing a new life-style (because of age, poverty, etc.).

Bereavement involves a failure to cope with the events of the world, and as such is extremely stressful, and results in a morbidity in its own right. Figure 18.1 shows data from a study by Parkes in which

he compared the mortality of widowers with that expected on an actuarial basis. Mortality was higher than expected for the first four years after loss, primarily as a result of cardiovascular disease (almost literally 'a broken heart'). Bereavement is also associated with depressed immunological functioning for six or more months after loss. Patients often cope with stress by resorting to drugs, not only of those prescribed for them, minor tranquillizer use being common, but also the 'social' drugs, of tobacco and alcohol, which can result in medical problems in their own right.

As in the case of the dying patient, we may ask how the doctor can help with bereavement. Perhaps the most important way is in realizing the existence of the problem. The bereaved consult their doctors at an increased rate during the first year of loss, and an awareness of their needs, and of the real reason for their visits, is often of great comfort. Just talking is beneficial; 'Give sorrow words. The grief that does not speak, knits up the o'erwrought heart and bids it break', says Malcolm to the bereaved MacDuff in *Macbeth*. This is particularly important a month or two after loss, when grief is at its height, but the social support networks of family and friends have diminished as mourning ceases. Help is often available from voluntary self-help organizations, such as *Cruse*, which is particularly concerned with the problems of young widows with children, or the *Society of Compassionate Friends*, for parents who have lost children. The grieving are searching for something that cannot be found, and are not finding that which is available around them; support networks of any sort will help them find what is to be found in life, and to start living again.

Most of this section has been devoted to the most severe form of bereavement, of a spouse. However much loss involves grief, albeit on a lesser scale, and Parkes has summarized the seven major characteristics of bereavement reactions of any form, which are common to many situations of loss, not only in medicine, but in life in general; a failed love-affair, failure at an exam, moving house, illness or accident, or even the simple process of ageing, all involve loss of something, and can be the subject of grief.

'1. A process of realisation i.e. the way in which the bereaved moves from denial or avoidance of recognition of the loss towards acceptance.
2. An alarm reaction—anxiety, restlessness, and the physiological accompaniments of fear.
3. An urge to search for and to find the lost person in some form.
4. Anger and guilt, including outbursts directed against those who press the bereaved person towards premature acceptance of his loss.
5. Feelings of internal loss of self or mutilation.

6. Identification phenomena—the adoption of traits, mannerisms, or symptoms of the lost person, with or without a sense of his presence within the self.
7. Pathological variants of grief, i.e. the reaction may be excessive and prolonged or inhibited and inclined to emerge in distorted form.'