

BMJ 1998;316:1521-1524 ( 16 May )

## Education and debate

### *Coping with loss*

## Facing loss

This is the last in a series of 10 articles dealing with the different types of loss that doctors will meet in their practice

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Series editors: Colin Murray **Parkes** and Andrew Markus

To conclude this series, I examine some of the problems that explain why the care that is needed in situations of bereavement and loss may not be provided, and I suggest some solutions.

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### Summary points

Losses may go unrecognised because they are concealed or avoided by those who experience them, misrepresented by caregivers, or take place very gradually

Losses are often concealed or misrepresented out of kindness, but the supposed harmful consequences of revealing the truth rarely match the harmful consequences of concealment

Men, military personnel, members of emergency services, and doctors are often expected to inhibit grief. They are also likely to find it difficult to ask for help

Even mothers who have planned for and eagerly anticipated the birth of a child may need to grieve for the many losses that result from it

The most important thing that members of the healthcare team have to offer to those who are afraid is a relationship of trust and respect, from which they can explore the situation they face, share the feelings that arise, and review the implications of loss

## ▶ Why losses may go unrecognised

Although the death of a spouse or child is a public event that seldom goes unrecognised, many other types of loss do not attract attention or support to those who suffer them. This has been called disenfranchised grief.<sup>1</sup> It is not unusual for more than one of the reasons listed in the box to apply.

People with unrecognised losses are of particular importance to members of the healthcare professions for three reasons: their physical and mental health may be at risk; they seldom come to the notice of the usual caring agencies; and we often find out about them because of our access to confidential information that is hidden from others. In fact we may be the only people who are in a position to help.

## ▶ Hidden losses

Hidden losses arise when a relationship has been kept secret, when the ending of the relationship cannot be acknowledged, or when the loss is associated with feelings of shame or inadequacy. If the bereaved person has had a homosexual relationship that has been concealed, the death of the partner may be a great cause for grief that the survivor may not feel free to express or share. Often the relationship has been known or guessed at by others who colluded by pretending that the relationship did not exist. The loss is not admitted to by anyone: the bereaved try hard to hide any expression of grief for fear that their secret will be discovered, and others are debarred from expressing sympathy or support.

There is a lot of truth in the saying "To understand is to forgive," and this applies to the patient as well as the doctor. People with secrets are often trying to hide from themselves—"If I don't tell anyone about it I won't have to think about it and can pretend that it is not true." Like most forms of denial this device is seldom successful because we have to be on our guard against the danger that we are trying to avoid. Once the secret has been shared we no longer need to be on our guard against it.

Trust has to be earned: we have no right to expect our patients to trust us and often have to address this problem before attempting to deal more directly with the secrets. By reassuring patients that anything they tell us will be treated as confidential and putting our case notes aside when confidential issues are touched on, we show sensitivity and earn trust. In the end, however, it is likely to be non-verbal messages—the welcoming smile, a hand on the shoulder at the right moment, a flash of eye contact when some particularly dangerous topic has been touched on—that indicate our trustworthiness.

### Why loss may go unrecognised

- Hidden losses associated with shame or stigma (for example, HIV infection or mental illness)
- Concealment or misrepresentation of losses by caregivers, as when caregivers conceal information from children or elderly people
- Gradual losses, as when the imperceptible progression of an illness is ignored (for example, in infertility or Alzheimer's disease)
- Avoided grief, as when people deny their need to grieve for social or other reasons (for example, in "macho" men after any loss or in mothers who have mixed feelings on the birth of a baby)

Problems of this kind are particularly common among people with HIV infection and other diseases that may be sexually transmitted. They are also common consequences of mental illnesses, which may be aggravated as a result of these problems.

Members of the healthcare team often have confidential information that may make us the only people who can give support to patients with such diseases. Some patients will shut themselves up at home, refuse necessary treatments, and resist attempts at rehabilitation. By criticising or browbeating them we only increase their feelings of insecurity and fear. By treating them with respect, withholding judgment, and encouraging them to believe in themselves, we stand a much better chance of helping.

Members of the healthcare professions may be the only people in a position to help people with unrecognised losses

## Assumptions about loss and principles of care

### Assumptions

Grief is an important experience that needs to be acknowledged

Losses that have been anticipated and prepared for are much less likely to give rise to later psychiatric and other problems than losses that are unexpected

Many of the losses that are met with in medicine affect the lives of members of the families of our patients

Grieving people tend to oscillate between avoiding and confronting grief; problems arise when either of these ways of coping predominates

Anger and shame can complicate the course of grief

The minority who are at special risk (people with traumatic losses, personal vulnerability and lack of social support) can be identified before or at the time of a loss

Losses can affect the carer as well as the cared for; doctors are not immune to grief

### Principles

Members of the caring professions have many opportunities to do this

By sensitively imparting information and support we can help people to prepare for the losses that are to come

It is the family, which includes the patient, that is the unit of care

Some people need permission and encouragement to grieve and reassurance of the normality of grieving

People may also need permission and reassurance that they do not have to grieve all of the time; they may need opportunities and encouragement to re-plan their lives in a way that values the past

We need to reserve judgment and show understanding

Members of the caring professions are well placed to assess risk, to give support, and advise those who need additional help how to get it

## Concealment or misrepresentation of losses by caregivers

Losses are often concealed or misrepresented out of kindness. A mother may not tell her young son that his father is dying because she wants to protect him from the pain that he will experience if he learns the truth. A nurse in a residential home for the elderly may not invite residents to attend the funeral of another resident because she thinks it will upset them. A doctor may give quite unjustified reassurance to a patient with heart disease for fear that the truth will cause the patient to drop dead.

In an important recent study, 50 people with learning disorders who were being cared for in the community and who had recently lost a parent were compared with 50 others who had not been bereaved.<sup>2</sup> Those who had been bereaved were unlikely to have been warned of the coming death of their parent and to have been taken to visit the grave, and only half were known to have attended the funeral. They had much higher scores on measures of anxiety, depression, hyperactivity, stereotyped movements, and other indicators of distress. Despite this, most of the professional and family carers who looked after them were quite unaware of their distress and inclined to attribute their symptoms to brain damage rather

than to bereavement and its secondary consequences.

Concealment of a loss often leads to bad consequences: the loss may eventually become obvious and the deception may be seen through; inaccurate information may leave the recipient ill prepared to deal with subsequent events; and an opportunity to help someone to cope with reality may have been missed. The supposed harmful consequences of revealing the truth rarely match the harmful consequences of concealment.

## ▶ Gradual losses

When a loss is very gradual or imperceptible, or the person has been born with a disfigurement or disability of which they only gradually become aware, they often succeed in ignoring or minimising the implications of the loss. So too do their family, friends, and caregivers, who may not understand that depression or other psychological symptoms are often indications that the person is becoming aware of the loss and that the time has come for someone to acknowledge the need to grieve and to support them through their grief.

The supposed harmful consequences of revealing the truth rarely match the harmful consequences of concealment

### **Infertility**

The infertile couple often deny for many years that they will never succeed in conceiving. As Bryan and Higgins put it, "Some secretly carry on hoping against all odds, if only to postpone the inevitable pain and misery of giving up hope."<sup>3</sup> They may not realise that their increasing irritability, their resentment of people who have had an abortion, and their loss of sexual libido are all symptoms of grief. When, eventually, they do acknowledge the true situation, each partner will grieve in an individual way and this may make it hard for them to support each other. Each may blame the other, for infertility is always assumed to be somebody's "fault." Not only is infertility inconspicuous, it is also something about which people often feel ashamed. Infertile couples often keep their sadness to themselves and social support from friends and family is lacking. Those unable to conceive may feel jealous of those who can and friends with children may not like to draw attention to their good fortune by sympathising.

Each partner in an infertile couple will grieve in an individual way, and this may make it hard for them to support each other

### **Alzheimer's disease**

Wives and husbands of people with Alzheimer's disease may be reluctant to acknowledge that they no longer recognise the person they married. Both social pressures from their families and allegiance to the spouse force them to pretend that the gross change in personality that has resulted from the disease has not impaired their relationship. Sadly, the failure to acknowledge the truth may cause them to blame the spouse for failing to be the sensitive, intelligent person he or she always was. Support and understanding may be needed if the wife or husband is to grieve for this very real loss and find a way of living with and supporting the different spouse whom they now have. When eventually the spouse dies, relief may make it hard to grieve at a time when everyone seems to expect it.

In these cases the understanding and support of members of the healthcare team can facilitate grieving, mitigate the feelings of anger and guilt that are inevitably present, and point the person towards the help of others who have experienced similar difficulties—through, for example, Issue (formerly the National Association for the Childless) and the Alzheimer's Disease Society.

## Avoidance of grief

Although most people oscillate between confronting and avoiding grief, extreme avoidance of grief always takes place for a reason. People may avoid grief because they are members of a family or a society in which grief is frowned on; they may avoid it because they fear the consequences if they should express it; or they may simply believe that they have more important things to do.

Cultural influences may determine when and how grief is expressed, and anthropologists have reported great variation from one society to another.<sup>4</sup> Whether or not the societal inhibition of grief within a culture is harmful is a matter for debate and research. One thing seems clear, however.

The wife or husband of someone with Alzheimer's disease may need support and understanding if they are to grieve for the loss of the person they married

Even within cultures there is great variation. Men, in particular, are often expected to inhibit their grief. This may explain the finding that, whereas women usually show more overt distress in the first year of bereavement than men and are more likely to seek psychiatric help, men take longer to return to the levels of adjustment of married controls than women.<sup>5</sup> They are also more likely to die from heart disease after bereavement than are women of the same age.<sup>6</sup> It seems that it is the inhibition of grief that is damaging to the heart rather than its expression. Bereaved men benefit more than women from therapies that encourage them to express feelings; bereaved women are more likely to benefit from help in reviewing and reshaping their assumptions about the world.<sup>7</sup>

Cultural pressures also prescribe when and whether grief is an appropriate response. Mothers who have babies are under considerable social pressure to rejoice rather than grieve. For many mothers to be, however, pregnancy is unwanted, and even those who have planned for and eagerly anticipated this event may need to grieve for the many losses that result from it. Kumar and Robson found that 10% of mothers had clinical levels of depression during pregnancy and 14% in the first three months thereafter.<sup>8</sup> Similar figures have been reported in five other studies reviewed by Brockington.<sup>9</sup>

A mother may experience considerable shame if, because of feelings of depression, fear, or grief, she is lacking in maternal feelings for her new baby. She is likely to be acutely conscious of the danger that her lack of feeling constitutes to her child. If she finds the courage to admit this, we need to recognise the seriousness of the situation and to reassure her that it is not her fault. If we help her through the period of emotional turmoil, maternal feelings will usually emerge. If they do not the mother will need and should benefit from the help of a child psychologist.

Those who overreact to loss will benefit from opportunities to re-examine their negative assumptions about themselves and their world

Another group who tend to deny their own needs to grieve are members of the caring professions, particularly doctors, who spend their lives caring for others but who often find it difficult to acknowledge their own emotional needs. If we accept that it is appropriate and therapeutic for our patients and their families to express grief, why should we deny ourselves that privilege? It would seem that, like soldiers and members of the emergency services, we are trained to remain calm in the face of danger. This leads us to the assumption that, even when the emergency is over, we have no need to get upset. Yet, as Bennet's paper in this series showed, such stoicism is bought at a cost and doctors who find ways to meet their own needs for emotional expression and support are likely become better doctors and to find greater satisfaction in their work.<sup>10</sup>

## ▶ Chronic grief

Some people become stuck in states of chronic grief that cannot easily be put aside; this may result from high levels of anxiety about the world that now exists. Grief is both an expression of distress and a cry for help.

A woman who has had a bad experience of pregnancy may experience high levels of anxiety and a propensity to depression which may spoil her next pregnancy. Similarly people who have recovered from mental illness may dread its return. If they experience a loss that triggers natural feelings of grief they may convince themselves that they are "breaking down," and this may indeed increase the risk that they will.

Those who overreact to loss will benefit from opportunities to re-examine their negative assumptions about themselves and their world, to review and replan their lives in ways that value and build on the past, and to venture forth into a world that seems more dangerous than it really is. Nothing succeeds like success, and quite small beginnings can lead to a restoration of confidence that eventually allows great progress to be achieved. There is much to be said for John Bowlby's claim that the most important thing that we have to offer frightened or grieving people is a "secure base," a relationship of respect—with a person who has the time, knowledge, and willingness to remain involved—that will last them through the bad times.<sup>11</sup>

The articles in this series are adapted from *Coping with Loss*, edited by Colin Murray **Parkes** and Andrew Markus, which will be published in July.

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## Education and debate

### *Coping with loss*

## The dying adult

This is the seventh in a series of 10 articles dealing with the different types of loss that doctors will meet in their practice

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This paper focuses on two common problems that arise when people come close to death, fear and grief. Fear is the psychological reaction to danger; grief the reaction to the numerous losses that are likely to occur in the course of an illness that is approaching a fatal outcome. Both can be expected to arise in patients, their families, and—though we are reluctant to admit it—in their doctors and other carers. Both fear and grief need to be taken into account if we are to mitigate the psychological pains of dying.

### Summary points

We should never assume that we know what people with terminal illness fear

Most patients will benefit if we can help them to feel secure enough to share their fears

Fear can aggravate pain, and pain fear

Patients with life threatening illnesses experience a series of losses as the illness progresses

Grief is natural and needs to be acknowledged and expressed

## Fear

Though it may seem obvious that people who are dying are likely to be afraid, we should not assume that we know what they fear. The box shows the fears, in approximate order of frequency, expressed to me by patients in a hospice. It is clear that fears of death itself come quite far down on the list. Difficult to quantify but of particular importance is reflected fear, the fear that people see in the eyes of those around them or hear in the questions that are not asked.<sup>1</sup> Many problems in communication arise out of fear, and

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we may need to take time to create trust and a safe place in which people can begin to talk about the things that make them feel unsafe.

### **Knowing about dying**

Few people in our society know how people die. Their image of death comes from horror comics, dramatic representations in the media, and the scare stories that get passed around a family when someone dies a painful death. To most people a little illness is bad; as the illness progresses they expect the symptoms to get worse, and it is logical to expect that, at the moment of death, every symptom will be as dreadful as it can be. This image of death as the peak of suffering bears little resemblance to the quiet slipping away of many a patient in the late stage of cancer whose symptoms are being relieved and who is surrounded by a loving family.

### **Causes of fear in people with life threatening illness**

- Fear of separation from loved people, homes, jobs, etc
- Fear of becoming a burden to others
- Fear of losing control
- Fear for dependents
- Fear of pain or other worsening symptoms
- Fear of being unable to complete life tasks or responsibilities
- Fear of dying
- Fear of being dead
- Fear of the fears of others (reflected fear)



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Patients who have learned to trust the doctor may well be able to share these fears and be reassured. But words like "cancer" and "death" are tainted with so many horrific accretions that it may be hard for the patient to use them. We may need to show by our own matter of fact manner that we are not afraid to speak the unspeakable. This does not mean that we should force people to face facts that they are not yet ready to face, but there are many ways in which we can ease things along. By inviting questions, answering honestly the questions that are asked (but not necessarily the ones that are not asked), and giving reassurance where reassurance is possible and emotional support to grieving when it is not, we shall often help patients and their families to make something good of the time that remains to them.

## **Fear builds on fear**

Fear often aggravates itself. Thus people with cancer may lie in bed worrying about their cancer. We do not need to know about the gate theory of pain<sup>2</sup> to know that a minor ache or pain will get worse if we worry about it. Though many of the pains of cancer patients are not directly caused by cancer, if we are to relieve them we need to take them seriously, discover their cause, and give an explanation and reassurance that will convince the patient.

The list of physical symptoms that can be caused by fear is long, ranging from the physiological effects of disturbance of the autonomic nervous system to the secondary effects of overbreathing. When they occur in people who are already physically ill the resulting tangle of physical and psychosomatic symptoms is not always easy to unravel. Although we often know that a particular case of cancer is likely to end fatally we can seldom predict how long it will take.<sup>3</sup> One of the hardest problems is living with uncertainty, and patients will often demand to be told how long they have to live. Doctors should not make predictions that will probably be wrong, and they need to be prepared to support their patients while they wait for the situation to clarify itself. It is often wise to resist pressure to carry out another operation or another battery of tests that will be unlikely to leave the patient any better off. Clearly, if we are to be of help we must tread a line between alarmist overinvestigation and facile reassurance.

## **Something can be done**

There is always something that can be done to help people through the long periods of waiting, be it a regular chat with a trusted doctor with whom patients can air their fears or a minor tranquilliser that may break the vicious circle of fear and symptoms. Diazepam still has a place in the short term treatment of anxiety, particularly in patients whose life is not likely to be long enough for habituation to become a problem. Several antidepressants, including 5-HT reuptake inhibitors (such as fluoxetine) as well as the more sedative of the tricyclics (such as amitriptyline and dothiepin), have anxiolytic properties that may benefit people who are anxious and depressed.

Cancer invades families, and it is important to reach out to all of those whose lives are touched by it. Support given to a patient's spouse indirectly helps the patient. That said, it is common to find that, as long as the patient is alive, members of the family will minimise their needs for help and support. We should be aware that things are not always as satisfactory as they seem. One way to tap into the needs of the family is to invite them to help us to draw a family tree. This not only tells us who exists, it also shows our interest and allows family members to share their fears and other feelings about each other.

## **▶ The dying patient's griefs**

Although the course of cancers and other fatal diseases can seldom be predicted, these diseases do tend to progress in a stepwise way. Initially the prognosis may not be bad—an operation and a course of radiotherapy or chemotherapy may offer the hope of cure, and most patients and doctors prefer to adopt an optimistic attitude. This does not mean that nothing has been lost. Quite apart from the physical mutilation and loss of function that can result from drastic treatments for drastic diseases, patients who have suffered a life threatening illness will never again be as secure as once they were. We need to be at hand and to encourage them to share their perception of the implications of the illness for their life.<sup>4</sup>

## Losses of patients with life threatening illness

- Loss of security
- Loss of physical functions
- Loss of body image
- Loss of power or strength
- Loss of independence
- Loss of self esteem
- Loss of the respect of others
- Loss of future

If people have been helped to express their grief at the losses that have occurred at an early stage of an illness, they will be more likely to be able to cope effectively when they are faced with another set of losses

### Expressing grief

If people have been helped to express their grief at the real losses that have occurred at an early stage of an illness they will be more likely to be able to cope effectively when they are faced with the next set of losses. After a period of relative quiescence a new symptom may arise; it is investigated and is found to indicate that the cancer has spread. This time it is more difficult to deny the fact that things are not going the way they should. Perhaps another course of chemotherapy is given, but the benefits are less and the patient's general condition is likely to be deteriorating. It becomes obvious that this person will never be able to return to work, and this may be a real cause for grief.

One of the most disturbing losses is the loss of the respect of others that is reflected in their expressions of pity, for pity, unlike sympathy, demeans the person pitied. To some extent this is counteracted if we and the patient's family continue to treat the patient with respect. The loss of respect will be aggravated if we patronise, infantilise, or denigrate the patient. The stages of dying described by Elizabeth Kubler Ross —denial, anger, bargaining, depression, and acceptance<sup>5</sup>—have rightly been criticised: they do not correspond to the unpredictable way in which most cancers progress.<sup>6</sup> Even so there is a tendency for people to move, in fits and starts, from a state of relative denial of the true situation to some kind of acceptance. Some never accept the situation and continue to expect to get better; others seem to embrace the prospect of death. In between there is a majority who oscillate back and forth between courageous attempts to face facts and episodes of optimism that are quite unrealistic. These fluctuations make it difficult to get reliable measures of "insight," and most research in this field is of dubious value. Anger and depression, which are frequent accompaniments of grief, and "bargaining," by which Ross means the attempts that cancer patients often make to accept one sacrifice in the expectation of a reward ("I don't mind losing my hair as long as I can be kept alive until my daughter's wedding"), are often found.

### Coping and letting go

In the later stages the loss of all of the appetites, including the appetite for life, makes acceptance easier. Many patients find it easier to "let go" of life because of this.

In all cases the patient's previous personality and their accustomed ways of viewing the world and coping with problems will colour the way they cope with illness and death. Those whose experience of life has left them confident in their own worth and trusting in the love of others usually seem to feel secure in the face of death; others, who may be less secure in both their confidence in themselves and their trust in others (and ultimately in God), may find it hard to step into the unknown. Spiritual values that arise from having found meaning in life make it easier to find meaning in death, but this should not be confused with

religiosity, which is often an attempt to propitiate God and seek God's protection. This kind of faith often breaks down when God fails to keep his side of the supposed bargain.

Whatever our own faith, it is important to respect the faiths of others and to resist the temptation to proselytise. Each person has their own religious language, and we must learn that language if we are to communicate successfully on spiritual issues. Many patients will enjoy the opportunity to share with us their attempts to make sense of their lives, and it is our privilege to be a part of this search.

## ▶ The doctor's grief

To help those who are dying we must be prepared to share their griefs and stay with them in their fear. Sometimes we have the satisfaction of knowing that the pain we have shared has been followed by a peaceful and even a triumphant end and this makes it easier to bear, but there are no guarantees. Sometimes death is a messy and a bitter business which leaves us harrowed and ashamed. Maybe the person who died has triggered off our own most dreaded fears; maybe we feel responsible for their suffering or their death.

At such times we too will need the support of someone we can trust—and we should not feel ashamed to ask for it. We too will need to grieve; if it is all right for our patients to cry, it should be all right for us too. We are not supermen and superwomen who can always be counted on to give help but never need it for ourselves, and we must be prepared to let others take over, for a while, the daily routines in order to give us space to grieve. It is a sign of maturity to know when to ask for help, and the wise doctor will have worked out systems of support to meet a range of needs.<sup>7</sup>

The articles in this series are adapted from *Coping with Loss*, edited by Colin Murray **Parkes** and Andrew Markus, which will be published in July.

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## Education and debate

### *Coping with loss*

# Blindness and loss of other sensory and cognitive functions

This is the fifth in a series of 10 articles dealing with the different types of loss that doctors will meet in their practice  
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Sensory and cognitive functions enable us to orient ourselves in the world; they make us aware of dangers and rewards; they mediate many sources of pleasure and of pain; and they are the means by which we receive messages from others. Anything that seriously impairs sensory or cognitive function is bound to have profound psychological effects, not only on the person who is affected but also on family, friends, workmates, and caregivers.

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### Summary points

- \_\_\_\_\_
- Sensory and cognitive defects disable all who come into contact with them, including doctors
- \_\_\_\_\_
- Fear, frustration, and grief are natural reactions in patients and their carers
- \_\_\_\_\_
- Denial of loss commonly impairs rehabilitation
- \_\_\_\_\_
- Anticipatory guidance and support after the loss can reduce long term problems

Sensory and cognitive losses disable the doctor as well as the patient. When we attempt to communicate with deaf people, their deafness renders us dumb. Blindness in our patients deprives us of the ability to use non-verbal communication. An aphasic person effectively teaches us what it feels like to be deaf. The brain damaged patient makes us feel stupid. We experience the same frustration as they do and some of the same pain.

## Problems with communication

The situation is particularly hard when the circumstances demand sensitive and empathic communication, for it is this very subtlety that is most difficult to achieve. The fact that, unlike the patient, we can escape from the frustration—by escaping from the patient—encourages us to do just that. We do our duty, inform them of the help that is available, then leave it all to them. We give up trying to communicate, avoid interaction, and inadvertently indicate that we wish they would stop troubling us. Consequently, it is common for patients with communication defects to feel that they have become a burden to all who meet them. They may be tempted to give up trying to cope with a world that feels unappealing and rejecting.

Yet communication is always possible, and the professional who is willing to take the time and make the effort to communicate with people in this situation can achieve a great deal. Most patients are reassured to know that we understand, even if there is no way in which we can change their situation.

We shall take blindness as our prime example of sensory loss and rely on the research of others to relate this to other types of sensory and cognitive loss. Our examination of the problems of adjusting to blindness stems from a study by one of us of 66 adult Londoners aged 21-65 years who were followed up for an average of five years after being registered as blind.<sup>1-5</sup> This research was supplemented by clinical studies and consultation with service providers for the blind, mainly in the United States, over a period of 25 years.

There are, of course, important differences between the reactions to sensory losses and to cognitive losses, mainly because it requires cognition for a person to understand that a loss has taken place and what this implies. For this reason the two types of loss will be considered separately.

## Sensory losses

### Onset

Most blind people are not born blind, they become blind.<sup>1</sup> This means that, having learned to rely on their sight in order to recognise and relate to the world, they must now radically revise their basic assumptions about that world. It is not surprising that blindness is usually an overwhelming personal and family catastrophe affecting the patient's mobility, work, personal relationships, and much else.

Although loss of sight is sometimes very gradual, three fifths of the subjects in the London study had less than a year between onset of symptoms and loss of useful vision, with 35% becoming blind in less than two weeks. Loss of hearing tends to be very gradual, and aphasia are more often sudden in onset. Those who experience a gradual onset have more time to prepare themselves for the changes that are occurring, but the changes are easier to ignore.

### Reaction to sensory losses

The box above shows the approximate sequence of reactions to loss of sight and the frequency with which the phenomena were reported when blindness was established. They resemble the reactions to bereavement and other losses.

## Reactions to loss of sight

- *Shock* or disbelief ("I didn't believe it was happening to me" or "It's not permanent")
- *Pining* for what is lost—for example, preoccupation with the visual past (83%), longing to see those things that cannot now be seen (97%), high anxiety and episodes of tearfulness (70%); pangs of grief for the visual world triggered by anything that forced the patient to confront the reality of blindness. These experiences were intensely frustrating and evoked feelings of irritability and anger
- *Depression* in 85% of blind subjects continued after the pining and accompanying tearfulness had declined
- *Resolution* often followed one or more turning points associated with increased self esteem and self sufficient acts such as preparing meals for oneself. The depression lifted and crying and social withdrawal diminished

Deafness evokes less sympathy than blindness. As the disability becomes established, deaf people go through the same succession of stages of reactions. <sup>6 7</sup> People with aphasia lose their jobs and other skills; they face social isolation similar to that of the deaf person, and their roles within the family undergo profound changes.

### Long term adjustment

Progress towards recovery occurred in less than half of the blind subjects studied. Anxiety and depression persisted in half the subjects, and substantial minorities had a lasting decline in self esteem, sleep disturbance, and social withdrawal. A quarter reported excessive weight gain and a third reported episodes of irritability and anger. Persisting pain in the eyes and headache were common and were often thought to be of psychogenic origin. Several young married men had lasting sexual problems, and people who increased their consumption of alcohol or tobacco seldom returned to previous levels.

Sensory and cognitive losses disable the doctor as well as the patient

Comparable difficulties have been reported after other types of sensory loss. In deaf people, psychiatric illness was reported in 19% and high levels of emotional disturbance in another 20%.<sup>8</sup> Much of this was associated with depression. Depression and feelings of worthlessness are also common in people with aphasia and sometimes amount to a "catastrophic reaction" when something happens that brings home the magnitude of the loss.<sup>9</sup>

### Determinants of poor outcome

A major correlate of delayed recovery from loss of vision was persistent denial of blindness: 53% of patients clung to an unrealistic hope of recovery and 58% refused to learn the skills necessary for adjusting to life as a blind person. A third had been to faith healers in the hope of recovering their sight. All too often unrealistic hopes had been kept alive by doctors who, out of a reluctance to upset the patient, pretended that there was still hope of recovery, often by arranging repeated and unnecessary examinations. Denial of blindness correlated with depression and the feeling of helplessness which regularly accompanies depression. It further undermined motivation and deterred efforts towards rehabilitation.

Similarly, deaf people commonly take a long time to accept that there is anything wrong with their hearing, and some never do. This interferes with attempts to persuade them to learn sign language or the other skills that are needed if they are to function effectively. People with a total loss of hearing often persist in attempts to use hearing aids long after these are of any value and may engage in a useless and expensive search for more effective models.



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People with defects and difficulties caused by sensory impairment or cognitive loss may turn away from people who attempt to communicate with them

Persisting physical ill health makes additional demands on people at a time when they are already at full stretch. Patients (particularly old people) find it hard to learn how to cope with sensory losses when they already have other health problems.

### **Preparation for and management of sensory losses**

It is usually possible to prepare people for the likelihood that they will lose their sight or hearing, and this will reduce the shock when it happens. In the long run, patients and their families appreciate the doctor being frank about the poor prognosis and the finality of the loss, if that is the case. It is also important for the doctor to be quite clear about the futility of seeking multiple opinions and undertaking wasteful treatments.

People need permission to grieve. They need recognition that this is a normal, natural reaction to loss and not a sign that they are "breaking down." Members of the family also need opportunities to share their grief as the impact of the patient's condition on their own lives becomes apparent. They need to be involved in the rehabilitation process from the start so that they become part of the rehabilitation team as well as recipients of its care. Failure to do this may bring about the situation in which an anxious wife or husband is undermining the team's effort to help the patient to become autonomous.

It is important for a member of the primary care team to be familiar with the network of rehabilitation services that are available and to ensure that the patient makes full use of these. If, as is often the case, agencies are slow to act, waiting lists are long, and paperwork burdensome, the patient and family must be prepared for this and supported through the waiting.

Warm and affectionate support of confused patients will often relax tension and improve cognitive function

Of particular value are opportunities to meet with veterans, other blind or deaf people who have achieved a reasonable level of adjustment. Many organisations for the blind, for example, have blind or partially sighted people on their staff, and there are mutual help groups run by and for blind people. In the United Kingdom the main organisation for the blind is the Royal National Institute for the Blind (RNIB); in the United States, the National Foundation for the Blind has chapters in each state. Group counselling has been shown to be effective and more of these groups should be established.<sup>10</sup> If, despite all our efforts, a person fails to meet our expectations of recovery from depression and to achieve a reasonable level of rehabilitation, we should not hesitate to refer them to specialist services.

## Cognitive losses

To communicate it is necessary to organise one's thoughts in a coherent way. Many of the problems of communication discussed above also exist when there is disease of or damage to the cerebral cortex, but some additional factors must be considered.

To grieve it is necessary to remember what you have lost. This simple fact explains the relative lack of grief that is found in patients with a severe dementia. Less severe forms of brain damage may, however, give rise to great distress. As long as people have sufficient mental function to realise what they have lost they can be expected to grieve; their grief, however, is likely to take different forms from that of people with intact cognition.

### Rapid onset

Cognitive losses of rapid onset (acute confusional states) cause much more distress than the insidious onset of dementia. The experience of disorientation can be very frightening, particularly in an unfamiliar environment. Anxiety itself impairs concentration and judgment, aggravating the symptoms that caused it in the first place. Well meaning nurses and doctors may be seen as strangers who are assaulting the person, and patients may hit out to defend themselves. The thought that we may be losing our mind is so frightening that it is likely to be denied. People will confabulate stories to explain the gaps in their memories and, because their cerebral function is impaired, these stories are often transparently ridiculous.

### Care of confused patients

The implications for care are clear. Whenever people are inclined to confusion we should try to maintain their orientation by providing them with reassurance and with simple and familiar cues. If they become confused at night we should turn on the light and talk clearly and reassuringly to them. Warm and affectionate support will often relax tension and improve cognitive function. Although tranquillisers are sometimes needed, they may aggravate confusion and it is wise to keep their use to a minimum and to tail them off as soon as possible.

It is often the partners and caregivers of confused patients, rather than the patient, who need a shoulder to cry on

### Progressive cognitive loss

In the more gradually progressive forms of cognitive loss (dementia) people have time to get used to their loss of memory and are less likely to become agitated. Even so, they may get upset if something forcibly brings home to them the fact of their loss of mental ability. Teasing relatives or angry staff who blame patients for being "stupid" may trigger a "catastrophic reaction" in which the patient may rush off, assault people who are to hand, or burst into tears. It is unkind repeatedly to remind brain damaged people of what they have lost in the mistaken idea that they need help to grieve.

Although the dementing patient's grief will usually grow less as his or her condition becomes worse, the same cannot be said of the grief of close family members. It is hard for a husband or wife to accept that the sensitive, considerate, and intelligent partner of 40 years has become forgetful, insensitive, and incapable of the degree of abstract reasoning necessary to see another person's point of view.<sup>11</sup> Many partners and other caregivers will deny the severity of the impairment and interpret the patient's behaviour as wilful or bad. It is often they, rather than the patient, who need a shoulder to cry on. Organisations such as the Alzheimer's Society can do much to educate and support carers.

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## Education and debate

### *Coping with loss*

# Surgery and loss of body parts

This is the fourth in a series of 10 articles dealing with the different types of loss that doctors will meet in their practice

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The loss of body parts can have distinct but overlapping psychological consequences. These can be bodily changes—alterations in the way patients, their families, and others perceive their bodies—or changes of function—alterations in the activities and roles that they are able to carry out. Some types of surgery affect one more than the other. Thus a unilateral mastectomy may have little influence on a woman's functional ability, but the effect on her body image will usually be profound. Most types of surgery, however, affect both form and function. Losing a limb is a clear example of this.

## Summary points

The loss of body parts can give rise to grief for loss of body image or function, or both

Anxiety, depression, and sexual problems are related to the magnitude and type of loss as well as the personal vulnerability of the patient

Both avoidance of and obsessive preoccupation with the loss can be problematic

Members of the caring professions can help to prepare people for the losses that are to come; reassure them of the normality of fear, grief, and their physiological consequences; introduce them to support groups; recognise and monitor any problems that may arise; and ensure that specialist help is given when needed

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## ▶ Amputation of a limb

The similarity between grief at loss of body part and grief caused by the death of a loved person has been clearly shown in comparative studies of the reaction to amputation of a limb and of widowhood.<sup>1</sup> People with either of these losses were preoccupied with feelings of loss: bereaved people were missing the lost person and the amputees were missing the loss of physical attractiveness (loss of body image) or the occupational and other physical functions that could no longer be carried out (loss of function), or both of these.

Both groups said that they had difficulty in believing in the fact of the loss and tended to avoid reminders. Both groups reported having clear visual memories of the lost person or part, and many had a strong sense of their persisting presence. This was most pronounced in the amputees as the "phantom limb." As time passed, both the phantom limb and the phantom spouse tended to dwindle in significance. In the case of the amputee, the phantom limb seemed to merge with the prosthesis. In both groups, returning to work was associated with improvement in emotional symptoms, but only a third of amputees were able to work full time, often because of persisting arterial disease in the unamputated limb.

Both before and after amputation, impairment of mobility often gave rise to depression, which in turn delayed rehabilitation. Like the widows, those amputees who had a longstanding tendency to anxiety or depression (described as "sensitisers" by Horowitz<sup>2</sup>) coped less well and suffered more than others. So, paradoxically, did a group of amputees, mostly men, who showed little evidence of distress at the time of the amputation. Rigid and compulsively self reliant people, they seemed to be coping well at first, but 13 months later they were significantly more likely to have persistent pain in their phantom limb than other amputees.<sup>3</sup> These compare with the "identification symptoms" reported by some bereaved people who show little grief at the time of a loss (Horowitz's "avoiders") but subsequently develop pains and other symptoms that often resemble those of the person who died. This suggests that the persistence of pain in a phantom limb may sometimes result from the repression or avoidance of grief at the loss.

## ▶ Cancer and cancer surgery

Cancer commonly causes loss of bodily functions, damage to the body image, and threat to life itself. Fear and grief are likely consequences, and the surgical and medical treatments for cancer are often drastic and may give rise to further losses. In a psychological sense cancer invades families, for many lives are likely to be affected by this illness.

People vary greatly in the degree of confidence and flexibility with which they cope with threatening situations. Several studies show that the intensity of distress following the onset of cancer is determined by such factors and by the degree to which people feel that the losses caused by the illness have made them different from others. This, in turn, can give rise to depression, problems of sexual adjustment, and other psychological difficulties.<sup>4-6</sup>

One indicator of adjustment, sexual functioning, gives an idea of the magnitude of the problem. Comparative studies are few, but the effect on sexuality is surprisingly similar in cancers as varied as Hodgkin's disease and cancers of the testis<sup>7</sup> and those of lung and prostate.<sup>8</sup> In both of these studies, between a quarter and a third of respondents in each diagnostic group felt that they had become lastingly less attractive to their partners, and a similar proportion found that their sex drive was diminished.



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Similar difficulties have been reported in women after mastectomy.<sup>9-11</sup> Many women are dissatisfied with any prosthesis that they are offered, and they may attempt to avoid facing the painful reality of their loss by refusing to look at their chest wall or allowing their partners to do so. Some go to the lengths of covering mirrors, dressing and undressing in the dark, and minimising the time that they spend bathing. These activities reflect an avoidant style of coping. It is hardly surprising that these women tend to have lasting depression and loss of interest in sexuality.

Although the psychological consequences of surgical mutilation can be severe, they need to be set against the anxiety that patients may feel if they fear that their cancer has not been completely removed. Lumpectomy has often been advocated on the grounds that it is less psychologically traumatic than mastectomy, yet in one study it was associated with a slightly higher incidence of anxiety states and depression than mastectomy.<sup>10</sup> Similarly, surgical treatment for carcinoma of the cervix has been shown to give rise to rather less reduction in sexual enjoyment and activity than treatment with radiotherapy.<sup>12</sup> On the other hand, between a quarter and a third of men who undergo surgical castration for cancer of the testis think that the operation has made them less attractive and less able to achieve sexual satisfaction,<sup>12</sup> whereas chemical castration for carcinoma of the prostate is associated with substantial improvement in psychological state.<sup>6</sup>

Whether or not patients with cancer have surgical treatment, they will usually have chemotherapy and radiotherapy, with loss of hair and other physical consequences. These are a further cause for loss of self esteem, grief, and depression.

## ▶ **Cardiac surgery**

Since cardiac surgery has little effect on the body image and most patients are likely to experience restoration of function rather than impairment, we might think that the psychological impact would be relatively slight and might be positive rather than negative. Yet in one study as many as 51% of elderly patients who underwent cardiac surgery had an adjustment disorder.<sup>13</sup> Why should this be?

The answer seems to lie in the special significance of the heart as the symbol and source of life, an internal clock that ticks our life away until it stops, dead. Cardiac surgery brings home to patients the seriousness of their illness and causes fear. The incidence of preoperative distress correlates with the

incidence after operation. In addition, open heart surgery may cause cognitive impairment, particularly in elderly people, making it harder for patients to cope with the emotional demands of the operation.

It is no surprise, therefore, to find that many cardiac patients remain fearful of exerting themselves and are apprehensive even when good cardiac function has been restored by surgery. This is most obvious in the sexual area and explains the occurrence of erectile dysfunction and loss of desire in these patients.<sup>14</sup>

## ▶ Preventing problems

Counselling, in the form of information and advice given before surgery, emotional support, and the opportunity to discuss problems that are anticipated, reduces the prevalence of psychological problems after mastectomy <sup>15 16</sup> and cardiac surgery.<sup>17</sup>

If an operation is planned the patient will need to be prepared for both the operation and its short term and long term consequences. Those about to undergo an amputation should be warned that a phantom limb, which may be painful, might persist for a while, and they should be invited to share any doubts or fears they have. This enables the carer to reassure them when fears are needless and to support them in grieving for the losses that are inevitable. It also increases the probability that the patient will agree to undergo the surgery. Such support has been shown to increase the probability that the patient will cope effectively with the loss.<sup>18</sup>

## ▶ Recognising problems after surgery

Despite the prevalence of sexual and other problems, they are detected and treated in only a small minority of patients. In one study of women undergoing mastectomy, not one had been asked a direct question about how she felt about the impact of surgery.<sup>19</sup>

Any person who has undergone surgery or other treatment that has led to the loss of a body part or function should be asked how they feel about the loss ("How have you felt about losing your breast?"). Patients should be asked about the effects on mood, day to day life, relationships, and sexuality ("Can you look at the scar?"; "Is it having any effect on your physical relationship?"). If there is evidence of mood disturbance it is important to establish whether this amounts to an affective disorder.

It is also important to discover how well the family is coping ("How does your partner feel about the effects of your operation?"; "Can you talk to your family about their feelings?"). A man who has lost a testis or a woman who has lost a breast needs to know that their partner still finds them attractive. When surgery is carried out in childhood it is particularly important to involve parents in the support system since overprotective behaviour can undermine rehabilitation.

## ▶ Management of problems

Despite some research which throws doubt on the lasting benefits of routine use of professional counsellors for stoma patients,<sup>20</sup> the kind of emotional support and information that can be given by a doctor or nurse is undoubtedly valuable to patients about to undergo major surgery. Other members of the patient's family, particularly spouses, will also need support.

"Avoiders" may need opportunities to talk through the implications of their loss and reassurance of the normality of grief and of its physical and emotional consequences. "Sensitisers" are more likely to benefit from meeting other patients who have undergone similar surgery and can help to reassure them that it is possible to live with disabilities.

Anything that increases mobility and enhances the patient's confidence and self esteem will facilitate the

necessary physical and psychological transitions.<sup>21</sup> Well conducted postoperative exercise programmes will restore patients' confidence in their bodies; this is particularly important after cardiac surgery when spouses, and even doctors and nurses, commonly aggravate patients' fears by treating them as if they were extremely fragile.<sup>22</sup> Organisations such as Cancer Link and Ostomy Clubs (for people with stomas) give neophytes opportunities to learn from veterans how to live with their disabilities.

People with damaged bodies may have longed for the day when they will again feel strong and safe. They approach surgery with a mixture of hope and dread. All too often their fear creates the very situation they dread. The physical manifestations of fear (which include the effects of both hyperventilation and autonomic disturbance) are easily misinterpreted as symptoms of bodily damage. It is important for medical attendants to provide positive reassurance and explanation for all such symptoms and to avoid unnecessary investigations (which only serve to convince patients that their doctors are as worried as they are). Anxiety management includes techniques for muscular relaxation and imaging (envisaging relaxing scenes and situations). Anxious patients may also benefit from anxiolytic drugs at times of particular stress.

The fact that someone who is clinically depressed has lost a limb or a breast does not mean that they will not respond to antidepressant medication, and there is no evidence that these drugs interfere with the process of grieving. When there are clinical indications for their use they should be given in full dosage and for at least four months.

Clinical psychologists have much to offer. Cognitive behaviour therapies challenge patients' misperceptions of themselves and can be helpful when body image problems persist. They are of particular value for disturbance of mood and sexuality associated with problems of body image.<sup>23</sup> Surgical correction of disfigurement can also have a positive influence on body image, and operations such as breast reconstruction and the re-siting or modification of stomas can have profound benefits. Patients should have realistic expectations and be properly prepared.

Although many sexual problems respond to appropriate education, reassurance, and support, those that do not may be helped by conjoint sexual therapy for both patient and partner. Sometimes a recent loss may uncover sexual and other problems that go back a long way. In all of these situations the general practitioner, who is likely to be the only person in a position to give long term support, is a key figure.

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BMJ 1998;316:856-859 ( 14 March )

## Education and debate

### *Coping with loss*

## Bereavement in adult life

This is the first in a series of 10 articles dealing with the different types of loss that doctors will meet in their practice

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Series editor: Colin Murray **Parkes**

Doctors are well acquainted with loss and grief. Of 200 consultations with general practitioners, a third were thought to be psychological in origin; of these, 55—a quarter of consultations overall—were identified as resulting from types of loss.<sup>1</sup> In order of frequency the types of loss included separations from loved others, incapacitation, bereavement, migration, relocation, job losses, birth of a baby, retirement, and professional loss.

After a major loss, such as the death of a spouse or child, up to a third of the people most directly affected will suffer detrimental effects on their physical or mental health, or both.<sup>2</sup> Such bereavements increase the risk of death from heart disease and suicide as well as causing or contributing to a variety of psychosomatic and psychiatric disorders. About a quarter of widows and widowers will experience clinical depression and anxiety during the first year of bereavement; the risk drops to about 17% by the end of the first year and continues to decline thereafter.<sup>2</sup> Clegg found that 31% of 71 patients admitted to a psychiatric unit for the elderly had recently been bereaved.<sup>3</sup>

Despite this there is also evidence that losses can foster maturity and personal growth. Losses are not necessarily harmful.

Yet the consequences of loss are so far reaching that the topic should occupy a large place in the training of health care providers—but this is not the case. One explanation for this omission is the assumption that loss is irreversible and untreatable: there is nothing we can do about it, and the best way of dealing with it is to ignore it. This attitude may help us to live with the fact that, despite modern science, 100% of our patients still die and that before they die many will suffer lasting losses in their lives. Sadly, it means that, just when they need us most, our patients and their grieving relatives find that we back away.

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## Summary points

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Losses are a common cause of illness; they often go unrecognised

---

Conflicting urges lead to a variety of expressions of grief; even so there is a pattern to the process of grieving

---

A knowledge of the factors that predict problems in bereavement enables these to be anticipated and prevented

---

Grief may be avoided or it may be exaggerated and prolonged

---

Doctors can help to prepare people for the losses that are to come

---

People may need permission and encouragement to grieve and to stop grieving

## Recent approaches to loss

A 1944 study of bereaved survivors of a night club fire focused attention on the psychology of bereavement, and led to the development of services for the bereaved and to other types of crisis intervention services.<sup>4</sup> It established grief as a distinct syndrome with recognisable symptoms and course, amenable to positive or negative influences. This, in turn, fuelled interest in the new fields of preventive psychiatry and community mental health. Elizabeth Kubler Ross's studies extended this understanding to dying people,<sup>5</sup> and helped to provide a conceptual framework for the humanitarian work of Dame Cicely Saunders and the other pioneers of the hospice movement.

More recently the improvements in palliative care have led to improvements in home care for the dying. Home care nurses have bridged the gap and general practitioners have had a central role, not only in caring for dying patients and their families but also in supporting people through many other losses. This is the main theme of this series, which draws together authorities with special knowledge of the losses which afflict our patients and their families and looks at the practical implications for doctors.

## The components of grief

Three main components affect the process of grieving. They include the urge to look back, cry, and search for what is lost, and the conflicting urge to look forward, explore the world that now emerges, and discover what can be carried forward from the past. Overlying these are the social and cultural pressures that influence how the urges are expressed or inhibited. The strength of these urges varies greatly and changes over time, giving rise to constantly changing reactions.



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Most adults do not wander the streets crying aloud for a dead person. Bereaved people often try to avoid reminders of the loss and to suppress the expression of grief. What emerges is a compromise, a partial expression of feelings that are experienced as arising compellingly and illogically from within.

Much empirical evidence supports the claims of the psychoanalytic school that excessive repression of grief is harmful and can give rise to delayed and distorted grief—but there is also evidence that obsessive grieving, to the exclusion of all else, can lead to chronic grief and depression. The ideal is to achieve a balance between avoidance and confrontation which enables the person gradually to come to terms with the loss. Until people have gone through the painful process of searching they cannot "let go" of their attachment to the lost person and move on to review and revise their basic assumptions about the world. This process, which has been termed psychosocial transition, is similar to the relearning that takes place when a person becomes disabled or loses a body part.

### **The course of grief**

- Numbness
- Pining
- Disorganisation and despair
- Reorganisation

## **The normal course of grief**

Human beings can anticipate their own death and the deaths of others. Unlike the grief that follows loss, anticipatory grief increases the intensity of the tie to the person whose life is threatened and evokes a strong tendency to stay close to them.

Although the moment of death is usually a time of great distress, this is usually quickly repressed and, in Western society, the impact is soon followed by a period of numbness which lasts for hours or days. This is sometimes referred to as the first phase of grieving.<sup>6</sup> It is soon followed by the second phase, intense feelings of pining for the lost person accompanied by intense anxiety. These "pangs of grief" are transient episodes of separation distress between which the bereaved person continues to engage in the normal functions of eating, sleeping, and carrying out essential responsibilities in an apathetic and anxious way.

All appetites are diminished, weight is lost, concentration and short term memory are diminished, and the bereaved person often becomes irritable and depressed. This eventually gives place to the third phase of grieving, disorganisation and despair. Many find themselves going over the events which led up to the

loss again and again as if, even now, they could find out what went wrong and put it right. The memory of the dead person is never far away and about a half of widows report hypnagogic hallucinations in which, at times of drowsiness or relaxation, they see or hear the dead person near at hand. These hallucinations are distinguished from the hallucinations of psychosis by the circumstances in which they arise and by their transience—they disappear as soon as the bereaved arouse themselves. A sense of the dead person near at hand is also common and may persist.

As time passes the intensity and frequency of the pangs of grief tend to diminish, although they often return with renewed intensity at anniversaries and other occasions which bring the dead person strongly to mind. Consequently the phases of grief should not be regarded as a rigid sequence that is passed through only once. The bereaved person must pass back and forth between pining and despair many times before coming to the final phase of reorganisation.

After a major loss such as the death of a loved spouse or partner, the appetite for food is often the first appetite to return. By the third or fourth month of bereavement the weight that was lost initially has usually returned, and by the sixth month many people have put on too much weight. It may be many more months before people begin to care about their appearance, and for sexual and social appetites to return. Most people will recognise that they are recovering at some time in the course of the second year.

## ▶ **Assessing the risk**

Much research, in recent years, has enabled us to identify people at special risk after bereavement either because the circumstances of the bereavement are unusually traumatic or because they are themselves already vulnerable (box). These risk factors can give rise to complicated forms of grief that can culminate in mental illness. A clear understanding of these factors will often enable us to prevent psychiatric disorder in bereaved patients.

### **Factors increasing risk after bereavement**

*Traumatic circumstances* Death of a spouse or child Death of a parent (particularly in early childhood or adolescence)

Sudden, unexpected, and untimely deaths (particularly if associated with horrific circumstances)

Multiple deaths (particularly disasters)

Deaths by suicide

Deaths by murder or manslaughter

*Vulnerable people* General: Low self esteem

Low trust in others

Previous psychiatric disorder

Previous suicidal threats or attempts

Absent or unhelpful family

Specific:

Ambivalent attachment to deceased person

Dependent or inter-dependent attachment to deceased person

Insecure attachment to parents in childhood (particularly learned fear and learned helplessness)

## Complicated grief

Bereavement has physiological as well as emotional effects (lower box). It also affects physical health: after bereavement, the immune response system is temporarily impaired <sup>7</sup> <sup>8</sup> and there are endocrine changes such as increased adrenocortical activity and increases in serum prolactin and growth hormone,<sup>2</sup> as in other situations that evoke depression and distress.

### Complications of bereavement

#### *Physical*

- Impairment of immune response system
- Increased adrenocortical activity
- Increased serum prolactin
- Increased growth hormone
- Psychosomatic disorders
- Increased mortality from heart disease (especially in elderly widowers)

#### *Psychiatric Non-specific:*

- Depression (with or without suicide risk)
- Anxiety or panic disorders
- Other psychiatric disorders

#### *Specific:*

- Post-traumatic stress disorder
- Delayed or inhibited grief
- Chronic grief

A variety of psychiatric disorders can also be caused by bereavement, the commonest being clinical depression, anxiety states, panic syndromes, and post-traumatic stress disorder. These often coexist and overlap with each other, as they do with the more specific morbid grief reactions. These last disorders are of special interest for the light that they shed on why some people come through bereavement unscathed or strengthened by the experience while others "break down."

It is a paradox that people who cope with bereavement by repressing the expression of grief are more likely to break down later than are people who burst into tears and get on with the work of grieving. The former are more liable to sleep disorders, depression, and hypochondriacal symptoms resembling the symptoms of the illness that caused the bereavement ("identification symptoms"). Not all psychogenic symptoms, however, are a consequence of repressed or avoided grief. Some reflect the loss of security which often follows a major loss and causes people to misinterpret as sinister the normal symptoms of anxiety and tension.

At the other end of the spectrum of morbid grief are people who express intense distress before and after bereavement. Subsequently they cannot stop grieving and go on to suffer from chronic grief. This may reflect a dependent relationship with the dead person, or it may follow the loss of someone who was

ambivalently loved. In the former case the bereaved person cannot believe that he or she can survive without the support of the person on whom they had depended. In the latter, their grief is complicated by mixed feelings of anger and guilt that make it difficult for them to stop punishing themselves ("Why should I be happy now that my partner is dead?").

Some degree of ambivalence is present in all relationships. To some degree its effects can be assuaged by conscientious care during the last illness, and many people will recall "We were never closer." If members the family have been encouraged and supported so that they have been able to care, and the death has been peaceful, anger and guilt are much less likely to complicate the course of grieving.

These two patterns of grieving often seem to occur in "avoiders" (people with a tendency to avoidance) and "sensitisers" (those with a tendency to obsessive preoccupation), respectively.<sup>9</sup>

## ▶ Preventing and treating complicated grief

Doctors are in a unique position to help people through the turning points in their lives which arise at times of loss. In order to fulfil this role we need information and skills. One of our problems as caregivers is our ignorance of our patients' view of the world. Not only do we seldom know what they know or think they know about the situation they face, we do not even know how that situation is going to change their lives. It follows that we need to find out these things and, where possible, add to their knowledge or correct any misperceptions, taking care to use language that they can understand. (This is easier said than done when words like "cancer" and "death" mean different things to doctors than they do to most patients.) Above all, we should spend time helping them to talk through and to make sense of the implications of the information we have given. If need be, we should see them several times to facilitate this process of growth and change. General practitioners, because they are likely to know the person, are often well placed to provide this "trickle" of care. For most bereaved people the natural and most effective form of help will come from their own families, and only about a third will need extra help from outside the family.

### **Anticipatory guidance**

Members of health care teams can often prepare people for the losses that are to come. People need time to achieve a balance between avoidance and confrontation with painful realities, and we need to take this into account when we impart information that is likely to prove traumatic. One way is to divide the information that needs to be confronted into "bite sized chunks." Doctors do this when we break bad news a little at a time, telling a patient as much as we think he or she is able to take in. Patients seldom ask questions unless they are ready for the answers, and they will usually ask precisely what they want to know and no more. It follows that we should invite questions and listen carefully to what is asked rather than assuming that we know what the patient is ready to know. By monitoring the input of information, a person can control the speed with which they process that information.

Although a little anxiety increases the rate and efficiency with which we process information, too much anxiety slows us down and impairs our ability to cope, our thought processes become disorganised and we "go to pieces." Anything that enables us to keep anxiety within tolerable limits will help us to cope better with the process of change. If we are breaking bad news (box) it helps to do so in pleasant, home-like surroundings and to invite the recipient to bring someone who can provide emotional support. A few minutes spent putting people at their ease and establishing a relationship of trust will not only make the whole experience less traumatic for them but it will increase their chance of taking in and making sense of the information which we then provide.

## Breaking bad news

- Consider social support (who to ask to be present)
- Consider setting (where to meet)
- Try to establish a relationship of mutual respect and trust
- Discover what the patient or the family knows or think they know already
- Invite questions
- Give information at a speed and in a language that will be understood
- Monitor what has been understood
- Recognise that it takes time to hear and understand bad news
- Give the patient or the family time to react emotionally
- Give verbal and non-verbal reassurance of the normality of their reaction
- Stay with the patient or the family until they are ready to leave
- Offer further opportunities for clarification, information, or support

## Supporting bereaved people

A visit from the general practitioner to the family home on the day after a death has occurred enables us to give emotional support and to answer any questions about the death and its causes that may be troubling the family. Newly bereaved people often feel and behave, for a while, like frightened and helpless children and will respond best to the kind of support that is normally given by a parent. A touch or a hug will often do more to facilitate grieving than any words.

During the next few weeks bereaved people need the support of those they can trust. We can often reassure them of the normality of grief, explain its symptoms, and show by our own behaviour and attitudes that it is permissible to express grief. If we feel moved to tears at such times there is no harm in showing it. Bereaved people may need reassurance that they are not going mad if they break down, that the frightening symptoms of anxiety and tension are not signs of mortal illness, and that they are not letting the side down if they withdraw, for a while, from their accustomed tasks. As time passes people may also need permission to take a break from grieving. They cannot grieve all the time and may need permission to return to work or do other things that enable them to escape, even briefly, from grief. It is only if they get the balance between confrontation and avoidance wrong that difficulties are likely to ensue. The first anniversary is often a time of renewed grieving, but thereafter the need to stop grieving and move forward in life may create a new set of problems. People may need reassurance that their duty to the dead is done, as well as encouragement to face the world that is now open to them. The most important thing we have to offer is our confidence in their personal worth and strength. We should beware of becoming the "strong" doctor who will look after the "weak" patient for ever, but this does not mean that we become angry and dismissive, reprimanding the patient for becoming "dependent." In the end, most bereaved people come through the experience stronger and wiser than they went into it. It is rewarding to see them through.

## Appendix

In the acute stages it is usually best to give support by personal contact, preferably in the client's home. Later the help of a group in which bereaved people can learn from each other, as well as a counsellor, may be helpful. Organisations such as Cruse Bereavement Care and the member organisations of the National Association of Bereavement Services may be able to provide either of these types of help. The Compassionate Friends (for bereaved parents), Lesbian and Gay Bereavement, Support after Murder and Manslaughter (SAMM), and the Widow-to-Widow programmes that exist in the United States and other

parts of the world provide mutual help by bereaved people for others with the same types of bereavement.

The articles in this series are adapted from *Coping with Loss*, edited by Colin Murray Parkes, which will be published in May.

### Further reading

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## ▶ Acknowledgments

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## Views and reviews

# On the Death of a Child

Celia Hindmarch Radcliffe, £ 12.50, pp 133 ISBN 1 870905 19 9

The death of a child is traumatic to medical staff as well as to the families who are bereaved. This is recognised with sympathy and understanding by Celia Hindmarch in her short book of practical guidance for those whose work brings them into contact with families who are losing or have lost a child.

Written in a simple, clear style, the book will appeal to nurses, midwives, social workers, and bereavement counsellors. It is not an academic treatise and lacks medical rigour. The references to medication and to psychiatric disorders are misleading. Thus we are told that antidepressants "impede decision making and delay grieving," whereas "something to induce sleep" is recommended. I am aware of no evidence that antidepressants influence the course of grief; indeed, they may be life saving in suicidal depression triggered by bereavement, and the newer antidepressants are relatively non-toxic. By contrast, the indiscriminate use of benzodiazepine sedatives and tranquillisers easily leads to habituation and may interfere with the grieving process.

Readers are given no guidance on the diagnosis of anxiety disorders, panic syndromes, post-traumatic stress disorders, or clinical depression, which are well recognised occasional complications of bereavement. We are given the impression that pathological grief reactions are the main problem that counsellors will meet, a conclusion that is not borne out in clinical practice.

**C. Murray Parkes**

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BMJ 1998;316:931-933 ( 21 March )

## Education and debate

### *Coping with loss*

## Bereavement in childhood

This is the second in a series of 10 articles dealing with the different types of loss that doctors will meet in their practice

**Dora Black**, *honorary consultant child and adolescent psychiatrist.*

Traumatic Stress Clinic, London W1P 1LB

Series editor: Colin Murray **Parkes** and Andrew Markus

Infants do not come into the world as "empty slates" but bring with them complex behavioural systems. One system that has been well studied protects the child from danger during the long period of extra-uterine immaturity. It involves the development of mutual attachment behaviour (box), which ensures that the child does not stray far from a caretaker. Infants are active partners in the development of this behaviour, using instinctive behaviours to engage caretakers in protecting them. These include smiling, vocalising, crying, and, later, returning frequently to the secure base of the adult after exploratory forays.<sup>1</sup> Infant attachment is at its height at about 3 years of age and then becomes increasingly diffused by the development of other relationships, but it remains important throughout life, with later relationships qualitatively echoing the earlier ones.

For optimal emotional, social, and psychosexual development to occur, children need a warm, secure, affectionate, individualised, and continuous experience of care from a few caretakers who interact with them in a sensitive way and who can live in harmony with each other.

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## Summary points

The pattern of attachment between infant and parent is rooted in instinct but modified by experience. It is an important source of security throughout life

The articles in this series are adapted from *Coping with Loss*, edited by Colin Murray **Parkes** and Andrew Markus, which will be published in May.

Separation from a parent in early childhood is followed, in succession, by protest, despair, and detachment; feeding difficulties, bedwetting, constipation, and sleeping difficulties may arise

In later childhood the loss of a parent commonly gives rise to emotional and behaviour problems

Children bereaved in childhood may be vulnerable to psychiatric disorder later in life

Forewarning can help children to prepare for bereavement, and they usually benefit from viewing a dead parent and attending funerals and other rituals

Family support meetings can reduce morbidity after bereavement

## ▶ Separation and loss in childhood

Infants and toddlers react to separation from an attachment figure by protesting vigorously. If their cries are not successful in restoring the adult, protest eventually gives way to despair, and eventually, if they are not restored to their attachment figure, pathological states of detachment and indifference may ensue. They probably have little concept of death, and the disappearance of a parent, whatever the cause, will evoke similar reactions. Thus a parent away for a few hours and one absent for longer both evoke the same separation anxiety in infants and toddlers older than a few weeks or months.<sup>2</sup> Even very young children can mourn for a lost parent, although the form of their grief differs from that of adults and older children.<sup>2 3</sup> Their reactions tend to be bodily ones such as feeding difficulties, bedwetting, constipation, and sleeping difficulties.

By 5 years of age, most children can understand the difference between a temporary separation and death. They know that death is irreversible and universal, has a cause, and involves permanent separation and that dead people differ from live people in several respects: they are immobile, unfeeling, and cannot hear, see, smell, or speak. It is more difficult for children to understand that dead people change in their appearance, and this concept does not develop until nearer puberty.<sup>4</sup>



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Children from 5 to 11 years are more likely to understand the physical changes that death brings and are helped by seeing these changes for themselves. They should be told what to expect, and they should be allowed to view the body if they wish. Exceptions may arise if the body is severely mutilated or if the child or parents have a strong aversion to the idea of viewing. In such cases additional support may be needed.

Children's characteristic response to the death of a parent is an increase in activity, and behavioural problems may result. Hallucinations of the dead person are a common feature of grief in adult life.<sup>5</sup> They can also be experienced by young children, who may interpret them as evidence of the parent's return, or as evidence of persecution by the ghost of the dead parent because of imagined shortcomings on the part of the child, in which case they can give rise to severe anxiety. Because of their need for parenting, children who lose one parent often become anxious about the survival of the other, and they may protect that parent from knowing of their distress. That, and the difficulty of sustaining mood states in childhood, may lead the parent or teacher to believe the child has recovered from, or has not been affected by, a bereavement.

## Components of attachment behaviour in infants

Behaviour that maintains attachment:

- Smiling
- Vocalising (babbling)
- Clinging
- Following

Behaviour on separation:

- Crying (protest)
- Restless searching
- High anxiety
- Irritability

## ▶ Reactions to bereavement in childhood

The florid reactions tend not to last beyond a few weeks, with most children regaining their previous

level of psychosocial functioning.<sup>6</sup> However, as assessed by parental reports, children have higher levels of emotional disturbance and symptoms than non-bereaved children for up to two years, and up to 40% of bereaved children show disturbance one year after bereavement.<sup>7 8</sup> In direct assessments of bereaved children, Weller and colleagues found that 37% of their sample of 38 bereaved prepubertal children had a major depressive disorder one year after bereavement.<sup>9</sup>

Longing for reunion is common and may lead to suicidal thoughts in bereaved children and adolescents, although they are rarely acted upon.<sup>9</sup> Other difficulties include learning problems and failure to maintain school progress.<sup>10</sup>

## ▶ Long term effects of bereavement on children

Children who are bereaved early are more likely to develop psychiatric disorders in later childhood.<sup>11</sup> Rutter found a fivefold increase in childhood psychiatric disorder in bereaved children compared with the general population.<sup>12</sup>

Adults bereaved of a parent in childhood seem to be more vulnerable than the general population to psychiatric disorder, particularly depression and anxiety, and this is often precipitated by further losses.<sup>13 14</sup> Attempted suicide is more common in adults bereaved in childhood.<sup>15</sup>

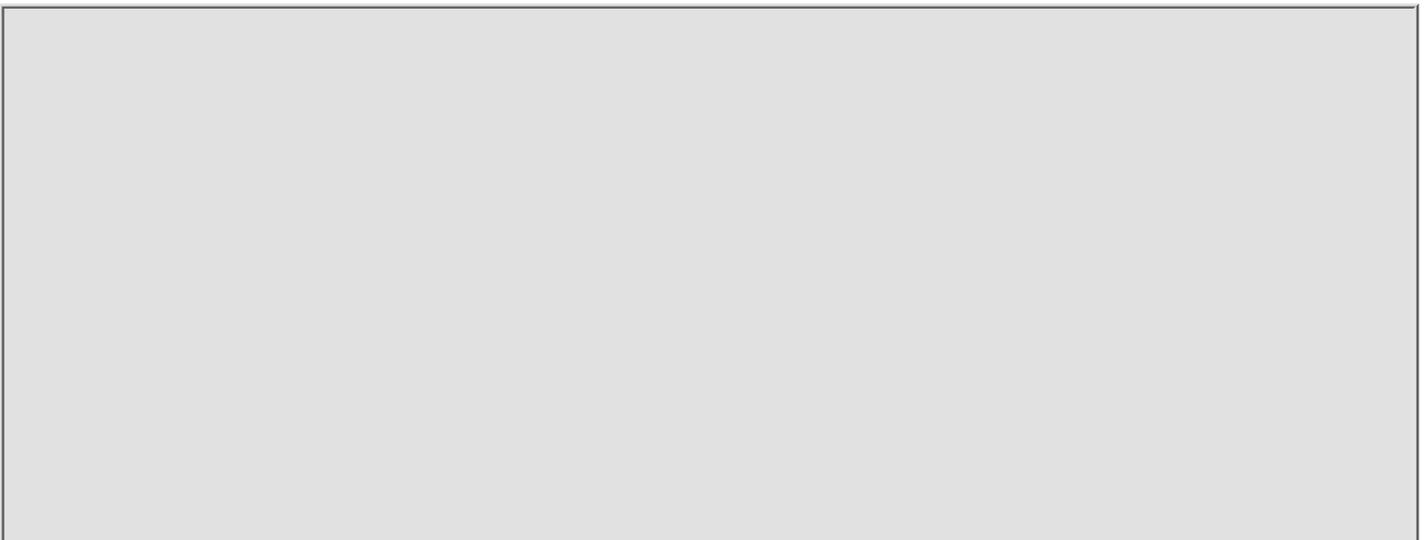
Children who lose their mother suffer a reduction in the quantity as well as quality of care, and this may account for the finding of differential effect according to the sex of the deceased parent.<sup>9</sup>

## ▶ Effects of the death of a sibling

Children compete for parental attention and often feel resentful of the attention given to a sick sibling. This can be heightened if a parent has spent time in hospital with the sibling. Guilt may be the predominant emotion that follows triumph at having survived when a sibling dies. Young children may believe that their hostile or ambivalent feelings actually caused their sibling's death, and this may lead to profound behavioural changes. If the sibling was older, and carried out some parental functions, the reaction may be similar to that after loss of a parent.

## ▶ Helping bereaved children

Children are rarely prepared for the death of a parent or a sibling, and yet we know from studies of bereaved adults that mourning is aided by a foreknowledge of the imminence and inevitability of death.<sup>16</sup> Children who are forewarned have lower levels of anxiety than those who are not, even within the same family.<sup>17</sup>





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Asked to draw her mother as she imagined she might be after radiotherapy for carcinoma of the breast, 6 year old Eva at first drew mother with a scarf to hide her bald head and then attempted to hide the scarf in a similar coloured background (purple). Subsequently she filled in the background with black and drew the "tombstone" below. Although she had not been told directly that mother was dying, she showed her therapist that she was aware of the likely future for her mother

When death occurs, young children in particular may need the concrete experience of seeing the parent after death. Bereaved adults find it particularly difficult to help a child in this way, and the general practitioner could offer to accompany the child. Similarly, children benefit from attending the funeral but need some protection from the raw expressed grief that may be shown at that time. Attending in the company of someone less affected by the death than the immediate relatives is desirable. This could be the child's teacher or someone from the family practice with whom he is familiar.

The monitoring and help with practical matters (applying for a home help, mobilising family support, ensuring adequate income, etc) needs to be accompanied by specific bereavement counselling for both the child and the surviving parent. A controlled trial of family therapy with children bereaved of a parent showed that the postbereavement morbidity of 40% at one year could be reduced to 20% by six sessions of family meetings which focused on promoting shared mourning within the family and encouraging communication about the dead parent. [8](#) [9](#) Preventive counselling is properly the responsibility of the primary care team, utilising the resources of bereavement counselling services as necessary. Cruse (the national charity for bereavement care) publishes useful literature for bereaved children and their carers and provides training and bereavement counselling services. Dyregrov's excellent handbook for adults deserves a place in a practice library, [18](#) and workbooks for children of primary school age can aid those counselling them. [19](#) [20](#)

Finally, the practitioner needs to be aware of the small number of children who may need more specialised help in recovering from depressive or other symptoms that may be associated with bereavement. These will include children who may have been partly instrumental in causing death (of a sibling perhaps), those who have gone through sudden and particularly traumatic bereavements, children who have suffered more than one bereavement, adolescents who express suicidal ideas, and children who do not respond to the initial preventive interventions.

## Acknowledgments

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BMJ 1998;316:1011-1013 ( 28 March )

## Education and debate

### *Coping with loss*

# Separation and other problems that threaten relationships

This is the third in a series of 10 articles dealing with the different types of loss that doctors will meet in their practice

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Series editors: Colin Murray **Parkes** and Andrew Markus

The secure or insecure attachments made to parents in childhood often prefigure the attachments which we make in adult life and predict the pattern of grief to which they give rise after the death of a partner.<sup>1</sup> This article examines the problems of change and loss that can arise within an established "pair bond" relationship and cause it to go wrong and, sometimes, to end. It focuses on the particular problems that may bring people into medical care.

Although people rarely come to their doctors complaining of problems in living, many psychosomatic and psychiatric disorders are caused by marital stress, and doctors often become aware that a patient is struggling with an unhappy relationship, or dealing with its loss, in the course of a diagnostic inquiry or a discussion of treatment procedures. In such cases an understanding of the emotional causes and consequences of relational problems, and how they might best be responded to, will be useful to the practitioner. I have covered these issues in more detail elsewhere.<sup>2-4</sup>

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## Summary points

Relationships are an important source of security and are influenced, for good or ill, by the expectations arising out of secure or insecure attachments earlier in life

Distrust undermines security and causes grief and anger which may further undermine trust

Children are often at risk when parental relationships break down

Relationships that are ending are a cause of grief in both parents and their children and may cause symptoms and requests for help

Doctors can reassure people of the normality of their grief, provide a safe place for its expression, and assess the need for specialist help

## Relationships in adult life

Marriages and similar relationships—all the strong pair bonds between adults, regardless of marital status—are not only partnerships in the management of personal and familial life but also adult attachments. They provide each of the partners with an emotional base with which is associated a sense of security.

Relationships arise out of complex associations between the mutual perceptions of the two people and their earlier experiences of attachments, particularly those to parents. These complex associations are further modified, for good or ill, by events within the relationship.

In the early days of the relationship, when the partners are together, each is likely to feel a sense of comfort or completion. They will be raptly attentive to the other. Each will have learned to associate the other's image and voice with feelings of security and wellbeing. If a marriage is reasonably happy, simply hearing the other's voice in a telephone call, or seeing the other's image in a photograph, can foster feelings of wellbeing.

### Problems in relationships

Problems can arise for various reasons. Sometimes the attachment of one or both partners is a reflection of an earlier attachment that was insecure and gave rise to distrust. When problems arise, as they will in all our lives, the partners may make negative assumptions about each other that belong to these earlier relationships rather than to the present situation. Alternatively, a new partner may fail to live up to idealised expectations arising from an earlier relationship. Whatever the cause, marital problems are devastating in their effects because the relationship that should foster security becomes a source of threat instead. Conversation is defensive, each partner protecting himself or herself against an expected assault by the other. Even when anger explodes into blind rage, other elements are being expressed by words and actions; these include despair, fear, and a misguided belief that the other can be intimidated into becoming once again a loving figure.

In many unhappy relationships, conflict is limited, and instead one or both partners withhold their love. At home, partners avoid each other. Each then feels utterly alone in the world: isolated within the relationship but unwilling to invite friends into an emotionally chilly household. A truly unhappy couple may not divulge just how bad things are without sensitive, sympathetic interviewing; each partner feels there is too much chance of being misunderstood. Yet it will be found that the couple no longer kiss, perhaps no longer eat together, and the spirit of cooperation necessary for working together is absent.

### Children and marital conflict

Some unhappily married parents are able, at least to an extent, to conceal from the child their feelings about each other and to show interest in and affection for the child. However, the child of such a marriage is likely to be aware of the parents' distance from each other, and underlying anger.

In general, children do not do well when their parents are unhappy with each other. Sometimes one of the parents establishes an alliance with the child from which the other parent is excluded. This imposes on the child impossible dilemmas of maintaining incompatible loyalties and unrealisable commitments. Children whose parents are preoccupied by their unhappy marriage are likely to feel isolated and alone. They may seek support from outside the family, from teachers or friends, or they may turn in on themselves or show other aberrant behaviour. Most children in unhappy homes make do, as best they can, with too little emotional and moral sustenance.

### Helping troubled marriages

Couples whose relationship is troubled can seldom be helped in a single session in their doctor's office; they are likely to need marital counselling. The doctor may have to strongly support this in order to overcome the couple's fear that counselling will make things worse. At the same time the doctor must be careful not to push the idea too strongly, in case one of the partners feels further alienated and further mutual disappointment ensues.



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## ▶ Separation

Should the couple separate, both partners are likely to be distressed. Unlike the grief which follows a loss by death, the grief of marital breakup is likely to be confused and mixed with intense anger, and to give rise to uncertainties about personal acceptability and worth.

The ending of relationships gives rise to mixed urges to re-establish the relationship coexisting with distrust of the relationship. Persisting tension is likely to express itself in preoccupations and in sleep difficulties. For a time each partner may experience an anxious, driving preoccupation with regaining the other, a preoccupation that can coexist with intense anger and determination to be rid of the other. Friends may take sides or may back off, leaving one or both partners socially adrift.

### Children and separation

Parents experiencing the separation distress that accompanies the end of the relationship are likely to have little energy for attending to the needs of their children. However, the children of a couple who are

breaking up will inescapably be distressed and in need of parental attention. They are likely to grieve over one of their parents departing from the home, to worry about the wellbeing of both parents, and to worry about their own wellbeing. If they are 9 or 10 or older they may express anger with one or both of their parents, despite their continued need for both parents' caring support. Their schoolwork is likely to suffer as they become preoccupied with their familial situation. Most at risk of negative consequences are those children who are recruited as allies by one or both parents or used by one or both parents as messengers to the other parent. Children do badly when put in the middle.

## ▶ **Custody of the children**

The parent who does not have custody of the children will have to deal with feelings of loss. Grief may be so intense and painful that it causes the parent to make unreasonable attempts to regain custody or to demand unreasonable access. Here the doctor can help by providing parents without custody an opportunity to express and work through their grief and by assuring them that their devotion to the children, despite its difficulties, will be recognised and appreciated by the children.

### **Helping at times of breakup**

People going through separation, particularly those with children, have many important decisions to make. At the same time, the parents are apt to be confused and unsure of themselves. Hence the parents are, at this time, likely to be unusually amenable to advice.

The doctor who becomes aware that a patient is going through separation from a partner can explore with the patient the extent to which help is needed. It may be enough to reassure a distressed patient that intermittent feelings of desolation are normal accompaniments of separation, and that such feelings will subside with time. The patient might also be cautioned that, although anger is natural in separations, it sometimes causes people to say and do things that they later regret. It may be useful for the doctor to schedule a further appointment with the patient for one or two months later, to be cancelled by the patient if things are going well. This demonstration of the doctor's continued concern and availability can in itself be helpful to the patient. If, in a second appointment, emotional problems seem to be becoming chronic, referral to a mental health professional may be justified.

## ▶ **The single parent household**

Single parents are likely to find themselves close to overload. If this occurs they may give up and become depressed, or they may turn to their children for help, no matter how old the children are. They often become easily irritated with their children. Feelings of being overwhelmed may make them tearful and overly anxious.

The doctor can help by giving reassurance, sympathetic understanding, and an appointment for a talk. There is, however, a limit to the degree of involvement that is appropriate, and the doctor should be prepared to refer patients needing more than occasional support to a mental health professional, social worker, or Relate counsellor.

## ▶ **New relationships**

Children may be apprehensive of a parent's new relationships; they may resent the new figure's entrance into their family. They are also likely to worry about how they can reconcile their continued loyalty toward their biological parent with acceptance of the new figure.

The parent's marriage to the new figure can make things worse, although it can also provide the parent with needed help and companionship. If the step-parent has children from a former marriage, the children

may worry that they will have to compete with their step-siblings for their parent's attention. They will also feel themselves required to adapt to a strange and often unappealing new family organisation.

The articles in this series are adapted from *Coping with Loss*, edited by Colin Murray **Parkes** and Andrew Markus, which will be published in July.

The doctor can be helpful to the children—and to the parent—by encouraging the parent to listen sympathetically to the children's concerns. This will reassure the children that they have not been deserted by the parent.

## Acknowledgments

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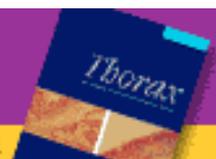
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BMJ 1994;309:583-586 (3 September)

## Education and debate

# Care of dying patients in hospital

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### Abstract

**Objective :** To study the process of care of dying patients in general hospitals.

**Design :** Non-participant observer (MM) carried out regular periods of continuous comprehensive observation in wards where there were dying patients, recording the quantity and quality of care given. Observations were made in 1983.

**Setting :** 13 wards (six surgical, six medical, and one specialist unit) in four large teaching hospitals (bed capacity 504-796) in west of Scotland.

**Subjects :** 50 dying patients (29 female, 21 male) with mean age of 66 (range 40-89); 29 were dying from cancer and 21 from non-malignant disease.

**Results :** Final period of hospitalisation ranged from 6 hours to 24 weeks. More than half of all patients retained consciousness until shortly before death. Basic interventions to maintain patients' comfort were often not provided: oral hygiene was often poor, thirst remained unquenched, and little assistance was given to encourage eating. Contact between nurses and the dying patients was minimal; distancing and isolation of patients by most medical and nursing staff were evident; this isolation increased as death approached.

**Conclusions :** Care of many of the dying patients observed in these hospitals was poor. We need to identify and implement practical steps to facilitate high quality care of the dying. Much can be learned from the hospice movement, but such knowledge and skills must be replicated in all settings.

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## Clinical implications

- Clinical implications
- More than half of terminally ill patients in Britain die in an institution, most in a general hospital
- Studies have suggested that the care of dying patients in hospital is inadequate
- Observations of 50 dying patients in four large hospitals showed that patients' symptoms were not adequately controlled and many received inadequate nursing care
- Patients received only minimal attention from most senior medical and nursing staff, their oral hygiene was often poor, their thirst remained unquenched, and they were given little encouragement to eat
- The skills developed in hospices must be learnt in hospitals if terminally ill patients are to die with minimal discomfort

## Introduction

Though most terminally ill patients indicate a preference to die at home,\*RF 1-4\* national statistics show that in the past two decades more than 60% of all deaths occurred in an institution.<sup>5</sup> Most of these deaths were in general hospitals.<sup>5,6</sup>

Several retrospective studies have attempted to assess the level of satisfaction with care in hospital during the final stage of life by means of the recollections of relatives or close associates.\*RF 7-13\* The findings indicate that, despite general satisfaction with the medical treatment, there is evidence of deficiencies in the service, including inadequate control of symptoms and failure to meet the physical, social, and emotional needs of the patients. More recent surveys have highlighted the distress experienced by patients and their families.\*RF 14-16\*

Few studies have reported systematically collected data on the process of care in hospitals.<sup>17,18</sup> This descriptive, exploratory study goes some way to redress this. The aims were to describe the nursing care of patients during the final six days in hospital and to identify factors that might influence that care.

## Methods

The study was conducted in four large teaching hospitals (bed capacity 504-796) in the west of Scotland, the data being collected during 1983. It was not prepared for publication earlier because of the untimely death of both academic supervisors and the appointment of the first author to a post in the Far East. Permission for access was given by the area health board and by the senior medical and nursing committee of each hospital. Investigations were carried out in 13 wards - six surgical, six medical, and one specialist unit.

Initially, interactions were monitored between 23 dying patients and 190 nurses (48 qualified and 142 unqualified). Notes were made of which nurses attended each patient, the care given, and the length of the interaction. Secondly, 91 ward rounds were attended; the content and length of the consultation between 14 consultants and a further 27 dying patients were noted. Communications between the consultants and 22 senior nurses concerning the dying patients were also noted, ward report sessions were attended, and nursing reports and clinical records were read.

The senior nursing officers in each hospital identified wards in which the criteria for the study were met (that is, an acute general ward where there were patients with varied nursing needs including a patient who was expected to die within six days). All nursing staff were informed that interactions between

nurses and the dying patient were being monitored. An approach was made to the consultants for permission to attend the ward rounds, the reason given being to elicit factors that might influence nurses during their care of the dying patient, including the influence of the doctor.

As a non-participant observer, one of us (MM) started regular periods of continuous comprehensive observations as soon as a ward met the selection criteria: these continued from 7 30 am - 1 00 pm and 5 00 pm - 9 00 pm for four days or until the death of the patient. The underlying premise for this tactic was that nursing should be observed amid the stresses and strains of the ward, so that the sociocontextual factors that might affect nurses' behaviour could be noted. The findings are illustrated by case reports describing the care of individual patients.

## Results

The mean age of the dying patients (29 women and 21 men) observed was 66 years (range 40-89). Twenty nine patients were dying from cancer and 21 from nonmalignant disease. Thirty five patients had not been expected to die during hospitalisation, but when recovery seemed impossible and death inevitable active medical intervention was modified for 33 of these. Two patients received aggressive interventions until death. Fifteen patients were admitted to die. The final period of hospitalisation ranged from six hours to 24 weeks. More than half of all the patients (29) retained consciousness until shortly before death.

### Interactions between nurses and patients

The ratio of qualified to unqualified nursing staff was 1:3. This was not reflected in the proportion of time the qualified nurses spent with the dying patients. Two of the 23 dying patients observed initially were not seen to have any contact with a qualified nurse, and 16 had only minimal contact (interactions lasting less than 60 seconds). Nursing care was provided predominantly by junior nursing staff, but the dying patients were usually alone: eight of the 23 were alone for at least 90% of the observation period, and all but one of the 23 patients were alone for at least three quarters of the time. As the time of death approached their isolation increased (see case reports 1 and 2).

### Case report 1

A 51 year old woman suffering from breast carcinoma with metastases was admitted to die. She was unconscious, and her breathing was rapid and noisy.

At 8 20 am she was moved into a side room, and two nurses attended to her for nine minutes. They then left the room leaving the door open. At 9 16 am the sister entered the room and checked the charts at the foot of the bed.

At 9 20 am the patient's breathing stopped. Twenty minutes later the ward team (senior registrar, resident, and sister) entered the room. They checked the charts, reviewed the intravenous regimen, and then left the room.

At 9 45 am the sister re-entered and changed the infusion unit as instructed. She was about to leave the room when she glanced at the patient. The screens were drawn immediately, and the door was closed. Death was certified as having occurred at 9 45 am.

### Case report 2

A 69 year old woman suffering from carcinoma of the sigmoid colon was admitted to die. She was responsive and lay on her side, breathing quietly with her eyes closed, in the centre of an open ward. At

10 15 am a large stain appeared on her pillow: the patient had stopped breathing.

At 10 30 her elderly husband arrived and was observed asking permission to enter the ward to visit his wife. At this point the non-participant role of the observer was abandoned, and the elderly man was diverted. When told by the ward sister of his wife's death he expressed a preference not to see her body and left.

The dying patients had many symptoms (see table). Two thirds of the patients did not receive adequate nursing care in accordance with the standards accepted by the Scottish health department<sup>19</sup> (for example, see case reports 3 and 4). The oral hygiene of 82% of the patients was poor: 56% had no attention given to this need. No consideration was given to the existence of anorexia or nausea, and the food provided was similar to that given to an average hospital patient. The nurses were heard at meal times to suggest that the patients "should try a little," but they did not stay to help. Thirst was not quenched for 56% of patients: the patients were often too weak to drink unaided (for example, see case reports 5 and 6). By contrast, the patients' physical state was recorded regularly - the temperature and pulse of 84% of the patients and the blood pressure of 48% were recorded until death.

### Case report 3

A 56 year old man was admitted to die. He looked dishevelled, neglected, and miserable. He was seen to smooth his hair with his hand and feel his rough skin. He received no attention to oral hygiene, bathing, or care of pressure areas during two days of observation. The nurses responsible for his care noted that the tasks had been done, though in fact he had received no attention.

### Case report 4

A 52 year old woman had metastatic spread involving the liver. She had gross abdominal distension, was icteric and very breathless, but was alert. Her conjunctiva were swollen and she shed icteric tears.

The patient received no care from the nurses delegated to give care. Yet in the nursing kardex it was recorded that attention had been given to her personal hygiene, pressure areas, oral hygiene, and eyes. This was inaccurate: her only attention had been to receive a commode from a nursing assistant. Contact time totalled six minutes in 4.5 hours of observation.

### Case report 5

A 57 year old woman was weak but alert. She lay sleeping but was roused by a nurse to have her temperature and pulse recorded. "Can I have a drink?" she asked.

"I'll be back in a few minutes," said the nurse. Fifteen minutes later a porter passed: "Eh mister, can I have some water please?" she asked. He smiled and passed on.

Ten minutes later a doctor passed: "Doctor, water please, "she said.

He looked over, approached a nurse who was attending another patient, and then returned and said, "It's coming."

Five minutes later the patient called out desperately, "Listen, a glass of water, please. All I want is water. I'm choking for water, cold water." At this point a nurse approached and offered the patient a drink. She took the glass and slowly drank the water.

### Case report 6

A 41 year old woman was dying from hepatic carcinoma. She had extensive abdominal distension. Her breathing was further complicated by her congenital deformities of a kyphosis and barrel chest. She was alert and was experiencing severe thirst.

At 5 25 pm a supper tray was placed before her, and she was lifted to the side of the bed and placed unsupported with her legs dangling over the side. Being unable to support herself, she fell back.

At 5 42 a cup of tea was placed on the tray. She struggled to reach the tea but was unable to do so. "Did you have a drink?" asked a nurse. There was no response and "120 cc tea" was recorded on the fluid balance chart.

At 5 50 pm the patient tried to reach a drink on her locker without success. At 6 05 pm she rolled over, drew in her legs, and tried to cover herself with her sheet.

At 6 10 pm the tray was removed with the food untouched; no contact was made with the patient. At 6 50 pm a member of staff placed a glass of water on the locker; there was again no contact.

Visitors attended the patient between 7 00 and 8 00 pm.

At 8 15 pm a nurse approached and asked the patient if she would like tea or coffee. "I've got juice," she replied. She tried to raise herself to reach the drink on her locker, but it was beyond her reach. She struggled but eventually lay back exhausted. She continued this struggle for half an hour, moaning as the nurses passed, and then called out at 9 20 pm to a nurse.

"What's wrong?" asked the nurse. The patient indicated that she wanted her juice. The nurse handed the patient her juice and then left (nine seconds contact). The patient attempted to drink, but could not keep her head up to do so. She could neither drink the juice nor lay the glass down on the locker, which was beyond her reach. She looked once more in the direction of the observer. Observations were discontinued, and the patient was helped to drink.

Symptoms experienced by 50 dying patients

Symptom	No of patients
Pain	34
Anorexia	30
Dehydration	28
Dyspnoea	26
Anxiety	20
Pressure sores	19
Depression	15
Faecal incontinence	13
Nausea or vomiting	10
Confusion or disorientation	4
Urinary incontinence	3
Dysphagia	2

## Ward rounds

Certain consultants (4/14) and senior nurses (7/22) were seen to have a greater number of encounters and longer contact times with the dying patients. They also showed characteristics that identified them as "caring" people: for example, they spent time with a patient, addressed the patient by name, established eye contact, touched the patient, and asked open ended questions and waited for an answer.

During ward rounds the four "caring" consultants conducted comprehensive consultations and showed a holistic approach to care. Attention was paid to both the physical and psychosocial needs of the patients. Nursing problems were identified, and, after discussion with the senior nurse, precise guidance was given on appropriate measures to provide comfort. The response of the patients to these interventions was reviewed and updated at each visit, and these consultants maintained contact with the patients until death.

The remaining 10 consultants concentrated on the patients' disease, the physical deterioration of the patients, and the attempted relief of some related symptoms. No reference was made to the patients' psychosocial needs apart from ensuring that their relatives had been seen. There was minimal or no personal contact with the patients. The time that these consultants spent at a patient's bedside was dependent on the continuation of active medical intervention. When active medical intervention was scaled down and death was imminent they withdrew from the patient, either remaining at the foot of the bed or passing the patient's bed without comment or with a brief aside to those in attendance such as "no change?" or "still there?"

A pattern of behaviour by the senior nurses was also noted. Three of the seven senior nurses who were identified as carers also acted as advocates for patients by outlining to the consultants aspects of need that required a medical input. These nurses were persistent until medical intervention gave adequate relief. This contrasted with the actions of their colleagues who introduced no aspects of patient care for discussion with the consultants but referred only to the recordings of the patients' vital signs.

When both the consultant and senior nurse in a ward team showed caring characteristics the dying patient had more contact time and more attention from qualified nurses and received an acceptable standard of care. Teams in which the consultant withdrew from the patient and the senior nurse had a similar tendency showed a corresponding deficit in patient care. In these circumstances the care of dying patients, by default, became the responsibility of the junior nurse or an unqualified nursing assistant.

## Discussion

"There is no better way to obtain data to describe a set of behaviours than to watch the persons behaving."<sup>20</sup> This observational study revealed that not only was there inadequate control of symptoms in dying patients but also that there was inadequate nursing care and minimal attention from most senior medical and nursing staff. Although these data were collected 10 years ago, current evidence suggests that the findings are still relevant to current practice. The findings on control of symptoms are in line with many other studies, which consistently show that terminally ill patients suffer severe and unrelieved symptoms<sup>3,6,11,14</sup> increasing in severity and frequency as death approaches.<sup>14,21,22</sup> Yet experiences in hospices and centres for palliative care indicate that it is possible to achieve good control of pain in about 95% of patients.<sup>23,24</sup> Other symptoms may be complex and sometimes difficult to control, but they also respond well to a concerted approach.<sup>25</sup> Adequate assessment and continuing monitoring are essential to achieve optimum relief.<sup>24,26</sup>

## Need for a holistic approach

Appropriate care of dying patients requires attention to all of the patients' needs,<sup>26</sup> a vital component of which is nursing care. Care and cleansing of the skin, constant care of the mouth, and the provision of adequate fluids and appropriate well presented food are all part of this care. These basic nursing interventions to maintain patient comfort were often not provided for most of the patients observed in this study.

Care extends beyond attention to physical needs: alleviation of individual patients' emotional, social, and spiritual problems should also be an integral part of their care.<sup>26</sup> This requires that time be spent with patients to identify their needs. This requires a commitment to and a personal interest in the patients.<sup>18,27</sup> As in other studies,<sup>28</sup> this was rarely observed: contact between nurses and the dying patients was minimal; and distancing and isolation of patients were evident, the isolation increasing as death approached.

Most of the consultants concentrated on the disorder rather than the person with the disease. Most senior nurses mimicked this behaviour by concentrating solely on the recordings of vital signs. For many patients there was little or no reference made to their specific physical problems or psychosocial needs. This threw into sharp focus the small group of senior medical and nursing staff who took time to be with the patient and who could be identified as carers by their attention to personal rather than technical matters. They identified all the needs of the person who was dying, explored various ways to give comfort, and initiated medical and nursing measures to provide relief.

#### Reasons for inadequate care

It is important to realise that most medical and nursing staff are motivated to provide quality care: there are many factors beyond their control that cause the care of dying patients to be less than adequate. These include lack of professional education,<sup>12,15,29</sup> busyness,<sup>11</sup> an inappropriate ward environment,<sup>1,7</sup> modern monetary and technological issues,<sup>30</sup> and tactics adopted by carers to avoid contact with dying patients.<sup>28,29,31</sup> Distancing tactics are a natural reaction of medical and nursing staff "to prevent them getting too close to the patient's psychological suffering ... to try to ensure their own emotional survival."<sup>31</sup> The outstanding question is how these attitudes and behaviours can be changed to benefit patients while simultaneously protecting carers. Creating a climate conducive to the practice of caring skills is essential, as is justifying time spent with a patient during the final stage of living. A recent paper describes some appropriate mechanisms for improving the quality of care of dying patients.<sup>32</sup>

#### Conclusion

In general hospitals medical care is concentrated on arresting disease and on recovery and rehabilitation. When death is inevitable palliative care must take priority over curative care. Our study suggests that this often does not happen. Yet dying patients are an integral part of the population of general hospitals. Their death should not be considered a failure; the only failure is if a person's death is not as comfortable as possible.

Only the forbearance of the patients who were dying and those close to them made this study possible. MM is grateful to them and to the staff in the clinical areas for their assistance and tolerance. Huw Davies is currently supported by the Clinical Resource and Audit Group (grant No CA 91/4) and has received much assistance from the North British Pain Association. Their support is gratefully acknowledged, but the views expressed are those of the authors and not necessarily those of the funding bodies.

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## Education and debate

### *Coping with loss*

## Loss in late life

This is the ninth in a series of 10 articles dealing with the different types of loss that doctors will meet in their practice

**Brice Pitt**, *emeritus professor of psychiatry of old age*.

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Series editors: Colin Murray **Parkes** and Andrew Markus

Old age can be seen as a succession of losses, gradual or sudden.<sup>1</sup> Stopping work means a loss of the working role, of the companionship of fellow workers, and of a full, structured day; it means a reduction in income—and, for those who live with someone, less time apart. Some people feel much diminished by retirement, hardly know what to do with themselves, and suffer a loss of status. Most developed societies do little to enhance the image of the "senior citizen," who is liable to be patronised, marginalised, or simply ignored and is seen as a problem for an overburdened welfare state.

There is a view, though, that successful ageing means compensating for some losses by making the best of change. So, the strains of having to commute, living for the job, and struggling to keep up are also lost; some pensions are at least adequate; there are concessions that make life a little cheaper for the over 60s. Having more time to oneself, for hobbies and interests, and to spend with partner are often regarded as benefits. Though it is usually a sudden event, retirement is (unless there is unheralded redundancy) expected and there is time to prepare for it.

### Summary points

In old age comes a succession of losses: dementia occurs in 20% of those over 80; loss of sexual enjoyment is common but not inevitable; half of octogenarians live alone

Depression in elderly people is often unrecognised; it is often caused by loss and, in turn, causes further losses

Preparation for retirement, health checks for the elderly, continued access to education, and the use of "at risk" registers can mitigate some of the problems of old age

The rationing and limitation of social support for the elderly is not justified

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## ▶ Many types of loss

Sensory loss afflicts most people as they age. Presbyopia is readily remedied by glasses, presbycusis less readily (or perhaps less acceptably) by hearing aids. These are very gradual processes, usually accepted without distress, though blindness or severe deafness is a different matter. Some memory loss may be normal with ageing; speed seems to be affected more than secondary memory, and verbal IQ is very well preserved.<sup>2</sup> "Benign" memory impairment<sup>3</sup> presents no serious problems, apart from the fear of dementia—which is, unfortunately, realised in a fifth of people over 80.<sup>4</sup>

It is not often acknowledged, except as a rueful and ribald joke, that loss of sexual enjoyment is common and distressing, and not an inevitable part of ageing.<sup>5</sup> Hormone replacement therapy and prostaglandins may do much to restore sexual function and enjoyment, but some older people are too shy to seek help, fearing that they should be "past it" and may be regarded as ridiculous or as "a dirty old man" (or woman).

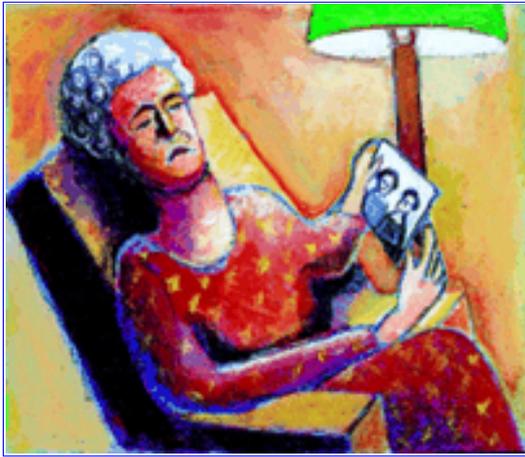
The risk of serious health problems—stroke, myocardial infarction, heart failure, falls and fractures, arthritis, obstructive airways disease, cancer—increases with ageing,<sup>6</sup> though many old people are spared serious infirmity until a short final illness. Those who are less fortunate suffer loss of comfort, mobility, and life expectancy. There is a risk of being widowed, especially for women, which represents a major loss after 40 years or more of being together.

Secondary to health problems (which make it difficult to get out and about), to reduced means (for transport and entertainment), and to the dying off of friends and family is isolation, which may be accompanied by loneliness. In Britain, about half of people 80 and over live alone,<sup>7</sup> and the extended family is stretched very thin by distance and relatively small numbers of children. Another secondary consequence of ill health, and most painful of all for many, is loss of independence.

Since long term care has become ever more arbitrarily and capriciously available from the NHS, old people who own property fear loss of estate. The desire to pass on the fruits of labour, success, sound investment, or good fortune to one's family is fundamental, and the power to do so may increase an older person's self esteem. Thus the costs of continuing care add to the problems of infirmity.

Reduced life expectancy is related to age and sickness. Through life a sense of immortality gives place to the shocking awareness of inevitable death, rapidly replaced (except in time of war, epidemic, or other crisis) by a feeling that it is a long time off or by denial. Birthdays like the 40th or 50th may precipitate fears of finality and an anxious review of achievements and ebbing potential. But still denial is a powerful buffer. Old people make long term plans and refer to peers as "old" but not themselves.

A new concern, as euthanasia becomes less theoretical and more real (as already in Holland and recently in the Northern Territory of Australia <sup>8 9</sup>), may be overlong survival, where life draws on without quality and the burden of infirmity falls on the family. While euthanasia may seem a boon to some, it could be felt to be a duty by others—to stop being a drag on the family's emotional and financial resources.



Old people suffer a succession of losses

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## Loss and depression

With so many vicissitudes it might be expected that the morbidity for depression in late life would be high. The evidence, however, is inconsistent and contradictory. While suicide rates peak in old age (for women in their late 60s, men around 80<sup>10</sup>) rates of depression are lower in older than in younger people. The epidemiological catchment area study in the United States found a prevalence of 2-3% in people over 65—a fifth of the rate in young adults.<sup>11</sup> Using a different instrument to diagnose depression, a survey of psychiatric disorder in general hospital inpatients aged over 16 in Oxford found that depression was least common in people over 70.<sup>12</sup> Younger people might be more open, older more guarded. Older people tend to somatise their emotional complaints, and these symptoms might erroneously be attributed to organic disease. Dementia might remove from consideration people who would otherwise have been recognised as depressed, or the researchers might have happened on an unusually contented cohort.

Rates of depressive disorders as high as 17% have been recorded in London,<sup>13</sup> and these accord with rates elsewhere in the United Kingdom found by using instruments specially designed for older respondents—the geriatric mental state examination<sup>14</sup> and its computerised form AGE-CAT,<sup>15</sup> and the SELF-CARE D.<sup>16</sup> Although the syndrome of depressive illness in late life is fairly common, the symptoms are far more so.<sup>17</sup>

Depression in old age is often undiagnosed and untreated

Why might depression be less common in older people? Depression carries a high mortality, so sufferers may not survive into old age. Today's oldest people are hardy survivors of poverty, large families, two world wars, and the pre-antibiotic, pre-welfare state era, and they tend therefore to be resilient. Possibly such benefits as central heating, television, allowances and entitlements, taken for granted by younger people, are appreciated by those who are older and once lacked them, and this offsets some of the losses; not having to work, for example, can be a great relief.

The likelihood, though, is that depression is more common in late life, but is frequently unrecognised. The evidence includes the high suicide rate, already mentioned. Barraclough's classic study of suicide in elderly people on the south coast of England showed that most were likely to have had depressive illness, had attended their general practitioners weeks before the act, and were being treated with tranquillisers,

hypnotics, analgesics, and laxatives but not antidepressants.<sup>18</sup> The evidence also includes the increasing rate of first admissions for depressive illness to psychiatric units in England and Wales (though it is more marked in women, from middle life the rate increases in both sexes with every decade, falling off only in those over 85)<sup>19</sup>; and the apparent failure of doctors to recognise depression in older people.<sup>20</sup> This lack of recognition may be due to lack of education, motivation ("drugs are likely to be toxic, counselling is hard to come by, and anyway it's hard to teach old dogs new tricks") or the somewhat ageist assumption that to be depressed in old age is both normal and justified.

The use of an "at risk" register and screening for depression may be good uses of finite resources

Depressive illness in late life often follows a major adverse life event, like bereavement or acute life threatening illness, but the association may not always be that the loss precedes the depression: depression may cause loss. Depressed people do not care to take care of themselves and may become ill, have accidents, and die from self neglect as well as deliberate self harm.

## ▶ What to do about it?

Marriage "till death us do part" was easier to honour when it usually meant 10-15 years rather than, as now, 40-50 years, as the high divorce rates in the more developed (and more aged) societies indicate. Shortage of housing is aggravated by the need of divorcees for two dwellings. A small consolation for high levels of unemployment is that, long before retirement age, many people have been prepared for not working and managing on reduced means. Others may benefit from preparation for retirement classes, and workshops are now provided by most large companies, trades unions, and professional bodies.<sup>21</sup>

"The comfortable state of widowhood is the only hope which keeps up a wife's spirits" (Mrs Peachum in *The Beggar's Opera*)

Health education not to smoke, to eat and drink moderately, to watch weight, and to take exercise may reduce ill health later in life. Health checks, either at set times (like the 75th birthday) or opportunistically ("as you're here, Mr Jones, tell me how you're enjoying your retirement while I check your blood pressure") are a good opportunity for health education. An "at risk" register may be a good use of finite resources for older people who have undergone recent life events—a recent move, illness, or bereavement, or who are known to have chronic infirmity or are living alone.<sup>22</sup> Screening for depression with, say, the geriatric depression scale<sup>23</sup> or BASDEC<sup>24</sup> is a good start to secondary prevention. A positive approach to the treatment of depression in old age is needed: perceiving the mood disorder underlying somatic complaints; using antidepressants with confidence, in sufficient dosage, and for long enough; and recognising the entitlement and likely efficacy of counselling for bereavement and marital problems and in the context of established depression. The consensus statement by the colleges of general practitioners and psychiatrists in 1995 was a good beginning.<sup>25</sup>

Further education is available in many daytime and evening classes and the University of the Third Age. Societies in which the fitter elders help their less able peers and seniors need not be a Utopian dream. Many retired people would and do like to "justify themselves by good works."

"Do not go gentle into that good night/Rage, rage against the dying of the light" (Dylan Thomas)

Finally, despair at the demographic time bomb, when there will be supposedly too many pensioners for

the remaining workers to provide for them, may have led governments into premature, panicky withdrawal of services. In the United Kingdom, the Community Care Act aimed to contain the costs of residential care, subsidised by social security, by transferring responsibility to local government. The consequence has been rigorous means testing, the expectation that people who have the means will contribute in part or wholly to their care, and, as budgets run short, rationing of care to those with greatest need. However, the "doomsday scenario" may be fallacious: though there will be a substantial percentage increase in octogenarians in the next 20 years or so, the increase in actual numbers will be small.<sup>26</sup>

The greatest cause of distress, dementia, may not necessarily prove to be intrinsic to aging. Donepezil can now provide temporary respite for 50-60% of people with early Alzheimer's disease,<sup>27</sup> and it is not too fanciful to expect the pace of research into the dementias to yield more lasting remedies that will offset the morbidity associated with an ageing population.

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## Education and debate

### *Coping with loss*

# The doctor's losses: ideals versus realities

This is the sixth in a series of 10 articles dealing with the different types of loss that doctors will meet in their practice

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After five years of study, newly qualified doctors may find it hard to realise that much of their future development will involve loss. They will go on gathering information and acquiring skills, but if they are to retain their enthusiasm and to mature as people, they will be learning to live with various losses.

## Summary points

Reality often disappoints the expectations of young doctors, who become tired and disillusioned with themselves and with the health care system

A plateau in middle life is often associated with loss of further opportunities, and high achievers may interpret this as failure

To enjoy medicine we must achieve a balance between meeting the needs of our patients and maintaining our own resources of strength, energy, and commitment

Doctors who can acknowledge their own fallibility, accept their own wounds, and accept help from colleagues or others may emerge warmer and more humane

## Tiredness

New doctors should enjoy the initial enthusiasm, the ideals and the sense of omnipotence and invulnerability, the buoyant feeling of being able to contribute to the general good, because it may not last for long. Very likely a few months of broken nights will blur the ideals and push the ambitions into the distance. The immediate objective becomes to get through the job.

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The grinding tiredness teaches them a lot: about their limitations, that sleep matters, and that it is difficult to be a good doctor when their eyes will not stay open. They become impatient over explanations, and tiredness comes up like a barrier so that they can no longer reach out to anxious and grieving patients.

They are learning that they cannot meet the ideals they set for themselves or the expectations of others. But tiredness is cured by a good sleep and enthusiasm is restored by a relaxing weekend. They can be admired for the long hours they work. They work harder than other people, they work amid the basic crises of living, they know about suffering, they see that people get better through their individual efforts, though they are not successful all the time. The death of a patient is a loss that reminds doctors of their limitations and the limitations of medical science, in which they had been taught to have so much faith. The first time it happens, the doctor is sad, shocked, perhaps angry that the patient could have done that to them.

## ▶ **Loss of unreality**

Most doctors have relatively simple lives in these early years, so it is possible, if they want, to give all their waking hours to the work in hand. Then there comes a time when the work is not sufficiently sustaining on its own—at least it ceases to be for most people, especially when the needs of others have to be considered. Now the people with the idealism and enthusiasm are confronted with a fresh reality, and much of a doctor's subsequent life and career will depend on how this matter is addressed.

This is a further lesson in the loss of omnipotence, but in no way is it the beginning of a decline. It is a time for redirecting energy. Doctors who accomplish this and can control the circumstances of their work can have a satisfying life, because medicine offers such abundant opportunities.

Many doctors make choices that put them in the front line, where they are directly exposed to needy members of the public. Here, the external pressures may seem always to be about to overwhelm them. The ideals are abandoned, and the redirection cannot be achieved. The giving out exceeds the individual's restorative powers. If as established doctors we find ourselves perpetually rushing to catch up with the demand as we see it, if our families tell us that we are irritable and our friends that we look tired all the time, then we are letting our resources become depleted: the signs of burnout will appear.

If, as doctors, we are to retain our enthusiasm and to mature as people, we must learn to live with loss

There is a phrase: "You have to be on fire before you can burn out." The idealism is gradually replaced by a mild cynicism, patients are perceived as inconsiderate and ungrateful, the telephone becomes an enemy. The process is familiar and, if unchecked, leads on to an apathy, in which minimum energy goes into the clinical work, although it may be redirected into administrative and extracurricular activities.



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### **Men and women have different experiences**

The traditional male approach has been to disregard these issues, at the outset of his career or later, and carry on up the professional ladder, regardless of personal considerations. If he becomes powerful enough he can sustain this style of life and put off his maturing, possibly forever. Sadly, these are qualities that make for professional success, and such people can be found among the more influential teachers of medical students, who are thereby exposed to the model of brashness and emotional immaturity.

Women doctors often experience loss before they qualify. They are affected more than most men by the brutalising aspect of medical education, which diminishes the empathic part of clinical work. They delay childbearing to their late 20s or beyond, and then they have to work that much harder to achieve the same professional goals as men.

### **▶ Loss of meaning, loss of spirit**

In the professional man's progress there are critical points, or hurdles, that can be cleared successively and that set him fair for the next stage. The loss of omnipotence is a necessary first stage. Another critical time for men comes in their late 30s, when they usually have their consultant post or their partnership in general practice. They are probably married with children, have a house, a good car, and a boat as well perhaps. The challenge here is that there are no more explicit challenges, such as qualifications and jobs; they have all been attained. Thus, there is a loss of these defining events and the excitement about all that is one day going to be. The doctor wakes one morning and says: "My life is now. This is what I am." This is the plateau of middle life.

High achievers imagine, albeit subconsciously, that the only way on from the plateau is downhill, and that once they have reached a particular professional peak there can only be loss of status, loss of role, diminishing health, and so on. The losses are real, but like all losses they are points of transition, which can be seized creatively. There are gains from this new state: it is no longer necessary to meet all the expectations of others, to keep on achieving or publishing; it is no longer necessary to be wise and in control. There is more time. Life can broaden out at this point, provided that the losses are understood and seen for what they really are.

Women suffer loss in the process of becoming doctors, but there are great benefits later on, and unfulfilled male doctors could learn from their female colleagues. A woman doctor has professional work that she enjoys and often she has a family; thus she is not looking solely to her job to give her a life that is

meaningful. Male doctors can do the same, only so often they avoid their families.

## ▶ Doctors going wrong

When their life can no longer be defined by achievement, doctors often fail to cope. The work has lost its meaning because there is simply too much of it or because the doctor has not adapted to changing circumstances. The issues of omnipotence and invulnerability appear again, but in a more subtle form: it is no longer a matter of one not being able to accomplish everything, but rather accepting that one is merely a vulnerable human being. This comes hard to powerful doctors, and they may try to avoid the transition in various ways: by blotting it out (through alcohol); by reassuring themselves of their potency (with a new relationship); by channelling their energies in new directions (by getting on the train to London, where the important committees meet); by developing symptoms and becoming depressed.

All losses are points of transition, which can be seized creatively

Most problems that doctors experience in middle life are essentially problems of meaning, and their lives have lost their meaning because they have not been able to make the fundamental transitions and to value themselves simply for being who they are.

### Confidential advice and support

There are currently many agencies for helping doctors. One example is the BMA's Stress Counselling Service (tel 0645 200169). It offers confidential telephone counselling 24 hours a day, 365 days a year, on a wide range of personal, emotional, and work related problems in areas such as:

- Debt and other financial concerns
- Workplace problems
- Difficulties with marital and personal relationships
- Alcohol and drug misuse
- Loss of confidence
- Stress and anxiety
- Bereavement.

Helpline numbers of two other agencies are 07071 223372 and 0121 558 0278.

## ▶ What is to be done?

It is good that schemes have been organised whereby doctors in difficulties can get confidential help at a distance from their places of work, but there is a measure of failure here. Doctors become involved in such schemes because they have not been able to share their deeper feelings with their immediate colleagues, or because problems have been neglected until the situation is out of hand and the doctor is ceasing to function competently.

These doctors are stranded. They have of course lost their omnipotence and invulnerability, and they are no longer climbing the ladder to success, but these losses are denied by them, so they are unable to make the essential transitions. It is as if they can accept themselves only as immaculate and all-competent professionals, and any blemish on that image is seen as a failure.

The losses are losses of illusions; the gains are gains in reality

In fact the blemishes have the potential to be a great advantage, and these doctors would do well to attend to the ancient idea that only the wounded physician heals. In myth it is presented in a literal form, but in ordinary life the "wounded" state refers merely to the acceptance of one's imperfections.

When doctors can accept their blemishes and vulnerabilities and their inability to achieve everything, they are free to make warm and ordinary relationships with their patients, family, and friends. They are free to look at the quality of their work and to make changes where these are needed. The losses are losses of illusions; the gains are gains in reality, and the quality of work and the quality of life can improve beyond recognition.

The articles in this series are adapted from *Coping with Loss*, edited by Colin Murray **Parke**s and Andrew Markus, which will be published in July.

### Further reading

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