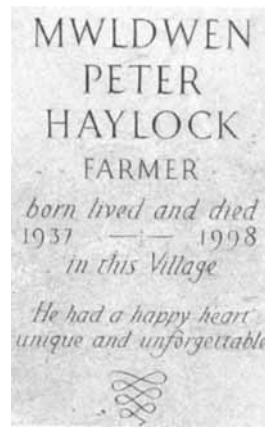


We also hope to establish a permanent exhibition of memorials, following the success of 'The Art of Remembering' exhibition (and accompanying book* of the same title) last year. The stones have a significance which is very powerful and many people said they came away feeling inspired and comforted. We think it important that passers-by also be moved, that they stop for a moment and wonder about the dead person.

Clients tell us that the process of finding a design and a form of words which properly reflect their feelings is very rewarding; most have a feeling of completion and many, a deep sense of peace and relief. Julie Haylock described what the creation of a memorial stone for her husband had meant to her:

[It] is the last thing you can organise for anyone, and I have found the whole process soothing and gratifying. The finished stone reflects exactly what I wanted to say. All the soul searching,



Detail of the lettering on the black stone designed and carved by John Green

heart wrenching, tear jerking experienced whilst looking for the right words – all worth while. I found the temptation was to say too much but in the end the simple statement, 'He had a happy heart, unique and unforgettable', completely encapsulates everything I had written down on reams of paper, trying to say everything that I felt needed to be said. In years to

come, people will stand and look at that stone thinking, 'There lies a happy farmer', and to influence the thinking of people who never knew Mel has been my goal.

There is absolutely no doubt that the whole process of commissioning a memorial can help the bereaved enormously. **BC**

*Both can be purchased from Memorials by Artists, Snape Priory, Saxmundham, Suffolk IP17 1SA. **T:** 01728 688934; **F:** 01728 688411. A free illustrated leaflet is also available



Secret Stones: an informal memorial made from a split boulder by Celia Kilner. 'Whatever we were to each other, that we still are.' Photo by Oliver Riviere

Disenfranchised grief



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Disenfranchised grief can be defined as the grief experienced by those who incur a loss that is not, or cannot be, openly acknowledged, publicly mourned or socially supported. Isolated in bereavement, it can be much more difficult to

mourn and reactions are often complicated. It is important to recognise and try to meet the needs of those whose grief is not acknowledged by society, whatever the emotional or financial costs.

In all of the following vignettes, some one has experienced a significant loss and, as a result of that loss, each is experiencing grief. Yet that grief is unacknowledged by others – it is disenfranchised.

- When Rita's best friend, Marsha, died, everyone asked Rita how Marsha's husband and children were dealing with her death. Rita's sense of loss was significant as well. Yet no one asked Rita about her grief.
- Tom, a young adult with developmental disabilities, experienced the death of his mother. But his siblings decided not to bring

him to the funeral. 'It would only upset him,' they reasoned.

- Carmen no longer feels she knows how to answer the question 'how many children do you have?' since her son committed suicide. She resents questions about the details, as well as the inevitable sense of pity or, even worse, a perception that somehow she or her family are to blame.
- After the divorce of his parents, Marcus began to act out at school. His parents were bewildered by the counsellor's remark that Marcus might be grieving. 'He sees his dad

whenever he wants,' Marcus' mother replied, 'it's not like he is dead.'

The concept of disenfranchised grief recognises that societies have sets of norms – in effect, 'grieving rules' – that attempt to specify who, when, where, how, how long, and for whom people should grieve. These grieving rules may be codified as personnel policies. For example, a worker may be allowed a week off for the death of a spouse or child, three days for the loss of a parent or sibling. Such policies reflect the fact that each society defines who has a legitimate right to grieve, and these rights correspond to relationships, primarily familial, that are socially recognised and sanctioned.

However these grieving rules may not correspond to the nature of attachments, the sense of loss, or the feelings of survivors and hence their grief is disenfranchised. In our society this may occur for a number of reasons, some of which are now discussed

EDITOR'S NOTE

Counsellors and members of the caring professions are often the only people who know of, and are in a position to help, those whose grief is hidden or unacknowledged. Ken Doka here summarises the main findings from his important book, *Disenfranchised Grief?* which found a name for the unnamed grievers whose sufferers need our special understanding and care.

THE RELATIONSHIP IS NOT RECOGNISED

Traditionally, in Western culture, kin-based relationships and roles are considered to be the most important, so grief may be disenfranchised in those situations in which the relationship between the bereaved and deceased is not based on recognisable kin ties. The closeness of other, non-kin relationships may not be understood or appreciated.

The roles of lovers, friends, neighbours, foster parents, colleagues, in-laws, step-parents and step-children, caregivers, counsellors, co-workers, and room-mates (for example, in nursing homes) may be long-lasting and intensely interactive but, even though these relationships are recognised, mourners may not have a proper opportunity to grieve a loss in public. At most, they might be expected to support and assist family members.

Many relationships may not be publicly recognised or socially sanctioned: for example, extra-marital affairs, cohabitation, and homosexual relationships have tenuous public acceptance and limited legal standing. Those in such relationships face having their grief and their relationship invalidated after the death of one partner, and others in their world, such as children, may also have to experience bereavement without acknowledgement or social support.

Even those whose relationships existed primarily in the past may experience grief. Ex-spouses, past lovers, or former friends may have lost touch, or had only limited contact with the person who has died. Yet the death of that significant other can still cause a grief reaction because it brings finality to that earlier loss, ending any remaining contact or fantasy of reconciliation or reinvolvement. Again, these grief feelings may be shared by others connected with the previous relationship, such as parents and children. They too may mourn the loss of 'what once was' and 'what might have been'. For example, a 12-year-old child of an unwed mother, never even acknowledged or seen by his father, still mourned the father's death since it ended any possibility of a future liaison. The community may not perceive that the loss of a past relationship could or should cause any reaction.

Nor does there have to be any actual connection to experience a loss. For example, many individuals can become quite committed and attached to celebrities whom they have never met, and may be profoundly affected by their death. The public displays of mourning for such diverse individuals as John F. Kennedy, Elvis

Presley, or Jerry Garcia, to name but a few, illustrate the intense private grief that individuals may experience. Clearly, in some cases, as in the death of Princess Diana, public displays of grief are permissible for those with no personal connection but, even then, for just a short time.

THE LOSS IS NOT RECOGNISED

In other cases, the loss itself is not socially defined as significant. Perinatal deaths lead to strong grief reactions, yet research indicates that others still perceive that loss to be relatively minor. Abortion, too, can constitute a serious loss, but the abortion can take place without the knowledge or sanction of others, or even the recognition that a loss has occurred. The public controversy on abortion may put the bereaved in a difficult position: many who affirm the loss may not sanction the act of abortion, while some who sanction the act may want to minimise any sense of loss. Similarly, we have only recently acknowledged the sense of loss that people experience in giving up children for adoption or foster care, and we have yet to take account of the implications this may have for surrogate motherhood.

Another loss that may not be perceived as significant is the death of a pet, despite research showing strong ties between pets and humans, and profound reactions to this loss¹.

Thanatologists have long recognised that significant mourning can occur even when the object of the loss remains physically alive, but often the reality of such a bereavement is not socially acknowledged. Sudnow, for example, discusses 'social death', in which the person is alive but treated as if dead², for example, those who are institutionalised or comatose. Similar problems occur in conditions of 'psychological death', in which the person lacks a consciousness of existence³, as in 'brain death.' One can also speak of psychosocial death, when the persona of someone has changed so significantly, as a result of mental illness, organic brain syndromes, or even transformation (because of addiction, conversion and so forth), that significant others perceive the person, as he or she previously existed, as dead⁴. In all of these cases, spouses and others may experience a profound sense of loss, yet that loss cannot be publicly acknowledged, for the person is still biologically alive.

THE GRIEVER IS NOT RECOGNISED

There are institutions in which the characteristics of the bereaved in fact disenfranchise their grief; therefore, there is little or

no social recognition of his or her sense of loss or need to mourn. Despite evidence to the contrary, both the very old and the very young are typically perceived by others as having little comprehension of, or reaction to the death of a significant other. Often, then, both young children and aged adults are excluded from discussions and rituals.

Similarly, those who are mentally disabled may be disenfranchised in grief. Though studies affirm that the mentally retarded are able to understand the concept of death⁵ and, in fact, experience grief⁶, these reactions may not be perceived by others. Because the person is retarded or otherwise mentally disabled, others in the family may ignore his or her need to grieve. Here a teacher of the mentally disabled describes two illustrative incidences:

Susie was 17 years old and away at summer camp when her father died. The family felt she wouldn't understand and that it would be better for her not to come home for the funeral.

Francine was with her mother when she became ill and was taken away by ambulance. Nobody answered her questions or told her what had happened. 'After all,' they responded, 'she's retarded'⁷.

THE DEATH IS DISENFRANCHISING

There are also cases in which the circumstances of the death create such shame and embarrassment that even those in recognised roles (such as spouse, child or parent) may be reluctant to avail themselves of social support or may feel a sense of social reproach over the circumstances of death. Death from a disease such as AIDS or from suicide or other self-destructive causes (eg drink-driving, drug overdose, etc), or even in certain situations of homicide, may all be illustrations of disenfranchising deaths. Each of these circumstances may carry a stigma that inhibits survivors from seeking or receiving social support.

THE WAY AN INDIVIDUAL GRIEVES IS NOT VALIDATED

Disenfranchised grief may also occur when individuals fail to mourn in a socially acceptable way. In some cases this may involve patterns related to gender. Doka and Martin⁸ have suggested that many men and some women may experience and express grief in ways that are more cognitive and active than emotive. Others may not see this as a pattern or expression of grief, but as its absence. For example, a father found great solace in maintaining a scholarship fund in memory of his daughter, but his wife found it hard to understand how he could be so involved in this fund when his daughter had

just died. In other situations, cultural variations in ways of mourning may cause others to discount a different cultural expression of grief.

OTHER SITUATIONS

These contexts are not exclusive. In some cases grief may be disenfranchised for a number of reasons. For example, a foster parent who cares for an HIV-positive child that later dies may fit into three categories: their role as a foster parent may not be recognised; others may think that in agreeing to care for a child with a life-threatening illness they understood and anticipated the death, thereby minimising the loss; and foster parents may be reluctant, given the stigma of AIDS, to share their experience of loss of loss.

Nor are these descriptions exhaustive. They are merely illustrations of the kinds of losses that may be disenfranchised. Since the publication of these ideas in *Disenfranchised Grief*⁹, research has included studies of many different situations, including adult children of dysfunctional families¹⁰ and adolescent romantic relationships¹¹.

Even the contexts may be viewed differently. For example, in a recent publication, Corr¹² suggested enhancing the concept of disenfranchised grief by recognising that any aspect of the grieving situation can be disenfranchised, from the context of bereavement to ways individuals grieve and mourn. To Corr, over time, all grief eventually becomes disenfranchised.

IMPLICATIONS AND CONCLUSIONS

There is a paradox to disenfranchised grief: often its very nature exacerbates grief. While each situation yielding grief is distinct, many may involve complicating factors such as concurring crises and ambivalent relationships.

In addition, since disenfranchised grief must preclude social support, there is often no recognised role in which mourners can assert the right to mourn and thus receive such support; grief may have to remain private. Though they may have experienced an intense loss, those whose grief is unsanctioned by society may not be given time off from work, have the opportunity to verbalise the loss, or receive the expressions of sympathy and support characteristic after a death. Even traditional sources of solace, such as religion, are unavailable to those whose relationships (for example, extra-marital, cohabiting, homosexual, divorced) or acts (such as abortion) are condemned within that tradition.

Although grief is complicated in these situations, many factors that facilitate

mourning are not present. The bereaved may be excluded from an active role in caring for the dying; they may not be able to attend funeral rituals, normally helpful in resolving grief; or the bereaved may have no role in planning those rituals or in deciding whether even to have them. After such losses as divorce, separation, or psychosocial death, rituals are lacking altogether.

That is why counselling can be essential. As Parkes¹³ has noted, grief counselling is critical in cases where social support is not readily available. Validation, sensitivity to the myriad losses people experience, and creative interventions such as devised rituals, may facilitate grieving.

Kammerman reminds us that there are complex costs to enfranchising the disenfranchised griever¹⁴, some of which are economic. Liberalising bereavement-leave policies for non-family losses has an economic cost to companies and is also difficult to monitor and enforce (eg it can be difficult to draw a line between a casual acquaintance and a good friend). He also suggests that the needs of family mourners may be lost in the countervailing claims of others who demand their right to grieve.

Yet the concept and challenge of disenfranchised grief expresses simple truths. Human beings have a great capacity to attach – to a wide variety of others, in our past or present, to people we do not even

know, even across species – and when there is a loss of that attachment, we grieve. Our goal, regardless of cost, must be to enfranchise the disenfranchised. **BC**

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LETTER TO THE EDITOR

Dear Editors

Did I detect a slight whiff of weariness in Colin Murray Parkes' Spring 1999 Editorial in *Bereavement Care*? He wrote, 'Bereavement seems to be generating a lot of words and it is valid to ask whether the effort needed to read them is worth it.'

One of my heroes, Duke Ellington, puts it a little more racy: 'Too much talking stinks up the place.' This was one of those principles which undoubtedly contributed to his 50 uninterrupted years as composer and band leader. Then I recalled the concluding paragraph of Parkes' introduction to the third edition of *Bereavement: Studies of grief in adult life* (Routledge, 1996), originally published in 1972, which reassuringly states that, 'despite numerous additions to the first and second editions...very little of the original accounts of bereavement and its consequences has had to be changed.' This is encouraging because it does feel as though there is 'too much talking' in the bereavement world.

Of course, the exchange of research and experience is vital, and complements and directs our own development as counsellors. But are we in danger of making bereavement another academic, elitist talking-shop? Might we lose sight of the client? Whilst I welcome new insights and 'tools of the trade' enabling me to help

clients as they struggle to relearn their world and regain themselves, I am more aware that I learn something every time I meet a client. When face to face with the chaos of grief, I am on my own. Then it's back to basics – empathising, holding, absorbing, reassuring, respecting – these skills, plus anything else that is relevant in the client's journey.

At times it feels a bit like improvising. True, the Duke had a score, a structure (if only on the back of an envelope!) but he left plenty of space for a particular musician to play as himself. Also the Duke regularly re-arranged and re-cycled his original compositions, thus keeping his music fresh and contemporary, but still highlighting the personal and distinctive sounds within the band. It is not too fanciful, I feel, to suggest that this process sounds a bit like bereavement counselling.

Finally, back to that Editorial. I welcome the fact that the Editors of *Bereavement Care* will not lose sight of us readers who attempt to meet the diverse needs of bereaved people, by continuing to sift, select and publish the type of material that will help us to do that.

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