Bereavement and Mental Handicap

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Some people back away from supporting mentally handicapped people who have been bereaved because they do not understand mental handicap, others because they do not understand bereavement. In this paper Fiona Cathcart explains that the needs of the mentally handicapped are not very different from those of other people faced with bereavement. Nobody needs to back away. **Editor**

A person with a mental handicap is often excluded from the everyday activities of life which other people take for granted. Access to work and leisure facilities may be restricted. There may be few opportunities to discuss decisions such as where to live or spend the day.

This exclusion happens in death as well as life. If the person has difficulty in understanding death, this is seen as a reason for giving less rather than more support. There is evidence that mentally handicapped people experience many of the emotions of bereavement but have fewer opportunities to resolve the grief.

The aim of this article is to describe some of the problems which may arise and suggest ways of dealing with them.

Death in the family

The bereaved child

One of the earliest papers was written by Ray[1] who describes two families in which the father died. In each, the surviving parent had thought that the handicapped child would not grieve because they would not understand what had happened. However, it was clear that the lack of comprehension added to their distress rather than reduced it. Each child went through recognisable grief, searching for the dead father and becoming angry or withdrawn when the reality of the loss became apparent.

> John's father died suddenly of a heart attack '. . . One night a man came to John's house and called his mother's name. She said "I've never seen John move so fast. He ran across the room but when he looked at the man and realised that it wasn't his Daddy, he just crumpled to the floor and started wailing." On another occasion, returning from a school trip, "He stood at the top of the minibus steps and searched the car park for his Daddy's car even though he could see his mother waiting for him . . . John continued to look at all the cars saying "Daddy" '.
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> Bill's father died of leukaemia. His mother felt he would not understand so told him his father was at work. '. . . Eventually he stopped wanting to go to the hospital. However, a couple of months later I had to go into town by bus and I took Bill with me. When the hospital came into sight, he started to make a fuss. He kept saying "gone to work" and wanted to get off the bus. He was very upset so in the future we avoided going past the hospital. Around this time, Bill became very withdrawn. Quite often, he would start to cry and when I asked him what was wrong he would keep repeating "gone to work".'

The limited comprehension did not lessen the emotional distress of these children and their behaviour was an understandable reaction to their loss.

The adult with mental handicap

The adult with a mental handicap may be treated as a child with no concession made to adulthood or achievements. If a surviving parent dies, the house and contents may be sold. As well as bereavement, the person can lose familiar possessions and sympathetic neighbours. There may be a change of neighbourhood. Staff and friends who have shared the daily routine at the local workshop or social centre for several years may be left behind.

Maureen Oswin describes with clarity and compassion how the person may lose everything familiar within a very short space of time. The plight of Joe[2] is not so unusual.

> '. . . Joe was aged 42 and had always lived at home. His elderly mother had been widowed for more than thirty years and Joe was used to being "the man of the house", having responsibility for the garden, locking up at night and winding the clocks. He attended a day centre and had many friends in the neighbourhood . . . When his mother died, Joe was found a temporary place in a hostel many miles from his home.'

Joe had five changes of residence in a few months after his mother died. Oswin comments that whatever distress is being experienced, it can only be made worse if the organisation and support given by the professional services is as insensitive as this.

Death in an Institution

The death of a family member will affect the rest of the family. Will it have the same impact if the person has lived in an institution away from the family, possibly for many years? Strachan[3] looked at residents in a large, long-stay institution who had been bereaved by the death of a parent or sibling in the previous year. They varied in age, length of stay in hospital and level of ability (Table 1).

Table 1—Description of bereaved residents (Strachan 1981[3])

Average stay in hospital	
17 years, range	1-48 years
Average age	
43 years, range	23-68 years
Male	14
Female	5
Severe handicap	10
Moderate handicap	9
Sudden death	3
Anticipated death	16
Parent died	17
Sibling died	2

He noted that few residents were able to maintain contact with the dying person during the illness and only three had attended the funeral. He suggested that hospital staff could have helped to include the resident: less than 20 per cent of the deaths had been unexpected. Usually it had fallen to nursing staff to tell the resident of the death.

Nurses reported little emotional response in the bereaved person during the first 24 hours. Less than half were tearful and only one cried for longer than minutes. Staff doubted that the loss had been understood. Only five people indicated clearly that they understood the permanence of the loss. They referred to the person's death and kept mementos. Nurses often observed '. . . there was no response to the death but he notices the loss of sweets and the chance to go out of the hospital . . .'

Two people had a noticeable change in behaviour. One man,

three to four weeks later, became more irritable, awkward, noisy, and wet his bed once. Another refused his usual activities, demanded more money for tea and cigarettes, and became agitated. He had been treated for paranoia before his bereavement and he relapsed temporarily.

Generally, there was an apparent lack of distress about the death of a relative. It may be that the grief passed unnoticed. One man, whom staff reported as showing little reaction, did share distress with his visitors and expressed anxiety about his future without his parent.

In contrast, when it was another resident who had died rather than a relative, other members of the ward seemed quieter, more anxious and tearful. The death was talked about a lot. The staff may have been more aware of grief in this situation because of their own sadness. Coping with death and bereavement is a major stress for hospital staff, and it can be particularly difficult for staff in a long-stay or residential setting who may have known the person for many months or years[4].

Strachan concludes by suggesting that:

- The hospital resident and the sick relative should maintain contact for as long as possible during the final illness.
- Family members should be encouraged to break the news because it is a family event. (I would disagree with this advice if the staff are better known to the resident than the surviving relative. A familiar and trusted nurse may be more appropriate than a strange relative who is upset and anxious.)
- The person should attend the funeral. The family may need to discuss this.
- Comfort and the opportunity for discussion should be offered.
- Simple explanations should be repeated as often as needed.

What Does a Bereaved Person Need?

Parkes[5] describes a bereaved person as someone who must change their internal model of the world to incorporate the new external reality. Bereaved people are shocked and disbelieving. The absence of the dead person from their shared routine and the rituals of the surrounding community help to overcome the disbelief.

It is a time of mental and physical confusion. A passer-by may be briefly mistaken for the dead person until a second glance reveals the truth. Instead of seeing the loved face, there are sympathetic looks, cards, wreaths and letters of condolence. Words of sympathy are heard, but not the familiar voice announcing its arrival home. There may be a need to talk at length about the dead person or the circumstances leading to the death. The need to search for the dead person may lead to physical restlessness which may be channelled into practical tasks such as clearing out clothing and personal possessions. Often it is disorganised activity and leaves the person feeling tired and drained. In addition, there are the social duties of registering the death, notifying appropriate organisations such as employers, writing to or telephoning other relatives and friends, as well as planning the funeral service and burial or cremation. All of these challenge the feelings of disbelief at the death and help the person begin to accept that the loss is real.

The person with a learning disability may experience any of the needs associated with bereavement but may face others too, particularly if there is a physical disability such as deafness or blindness. The person cannot experience sounds and sights such as the memorial service, receiving condolences and family reminiscences, all of which can help make the death real. If there are communication difficulties such as dysarthria, the ability to express grief and receive support through discussion can be limited or perhaps misunderstood. It has been suggested that seeing the body may help accept the reality of death[6], but there may be no opportunity for this. Individuals will vary in their understanding of different components of the concept of death such as universality and irreversibility[7].

Meeting the Needs

The person with a mental handicap should have access to the resources and support available to people without a handicap. These include opportunities to visit the grave and talk about the life with the dead person. Oswin[8] offers guidelines for those working in this situation (Table 2).

In addition, the specialist services with whom the person may already be involved could direct their sessions specifically to helping the person resolve the grief. The person may be part of a music or drama group which could help them express their feelings. Art therapy or occupational therapy may be particularly valuable for someone with limited ability to speak about the loss. The relationship with the dead person may be reviewed in paintings or collages which could incorporate photos or even pieces of fabric from a familiar garment. Some bereaved people choose to keep a favourite item such as a jacket for a long time after the other clothes have been given away. They say the familiar smell is comforting. Perhaps a person with very limited abilities could be comforted by a favourite garment made into a cushion which could be cuddled.

Table 2 — Recommendations for Good Practice (Oswin 1985[8])

1) Staff in organisations working with mentally handicapped people should be better informed about grief

2) Mentally handicapped people have a right to be told the truth and to grieve

3) Parents should try to have a plan of action in the event of a death

4) There should be a plan of action at Day Centres in the event of a client being bereaved while there

5) Immediate removal to unfamiliar accommodation should be avoided. A professional or volunteer could stay for the first few nights to ease the transition

6) Residential placements should be as stable as possible

7) Continuity of staffing is important, with an assigned keyworker if possible

8) Assessments are unreliable in the first few months because the person may be functioning at a lower level than usual because of their grief

9) If the home and its contents have to be given up, then the person must be able to take personal or significant belongings from it. (An item from the bedroom may be particularly reassuring, such as a familiar bedcover or a favourite chair.)

Helpful responses

There has been little written specifically for bereaved mentally handicapped people, but the recent books 'When Mum Died' and 'When Dad Died'[9] depict these situations with simple illustrations and with basic vocabulary in large print. Workbooks devised for children such as 'When Somebody Very Special Dies'[10] or 'Good Grief'[11] could be modified easily to meet the particular needs of a handicapped client.

Susie (seven years) has Down's syndrome. She was referred to a psychologist because she had become difficult to manage at home. She was biting, kicking and swearing and was in danger of losing her weekly session at the community school as well as her prized place in the local Brownie pack because of her behaviour. Her parents attributed this to the death of her grandfather who

lived nearby and of whom she was very fond.

Susie enjoyed looking through books and colouring. Some relevant children's books were given to the parents to read with Susie. It was thought this would help the family share the grief. Her parents were still grieving themselves and reading through the books and discussing them helped them to talk about their own sadness. The mother and daughter made up an album together about Grandad which included photographs and drawings of shared activities such as the play park. When the parents accepted their own loss it was easier for them to deal with the child's feelings of loss. They recognised Susie's other losses during that period such as the absence of her regular respite carer and also the increasing absence of her parents as they cared for the grandfather during his terminal illness. They regained confidence in their own ability to manage Susie's behaviour, which became less of a problem.

Research by Black[12] indicates that the ability of the child to cope with bereavement depends upon the surviving adults' mental health and the family's acceptance of tears and other overt expressions of grief.

Preparation for bereavement

I have suggested that people should have access to resources after bereavement, but there should be opportunities to discuss loss before bereavement as well Social education in schools should include discussion of loss. The development and maintenance of relationships is a focus for discussion, so why should dealing with the inevitable loss of relationships not be also?[13] The Social Relations programmes in Adult Training Centres which stop at adulthood are incomplete. Death is an integral part of the biological cycle of life. The video 'The Last Taboo'[14] can be used to stimulate a group discussion with some clients. It is helpful if parents can also discuss this, perhaps with the support and advice of local organisations such as Mencap or the Scottish Society for the Mentally Handicapped. They may wish to make provision in their will for the future care of their handicapped child. Recent literature offers guidance through the complex legal situation.[15, 16]

Hidden strengths

The future may offer more than had been hoped. When a bereaved person reflects on the experience, they frequently remark: 'I would never have thought I had the strength to cope with something like this.' Also, they develop abilities of which they had not thought themselves capable. A widow may learn to drive rather than sell the family car. A widower may learn to cook and make new friends through a local cookery class. Pincus[17] describes individuals who coped better or worse than expected following the death of a marriage partner. The person who was seen as weak may be unexpectedly strong, whereas the one who was considered the strong partner of a relatonship may seem lost. Similarly, people with mental handicaps may have potential which was unrecognised or given no opportunity to be developed. When their loss is resolved, they too can be stronger and more capable people.

Agnes was 40 years old and had poor eyesight. She was an only child and lived at home with her parents who had been told that she had a weak heart and any excitement or exertion could be fatal for her. She had no education and had been protected from all social activity. The family declined involvement with the statutory services. She was admitted to an institution on the death of her eldery deaf mother, father having died some years before.

She was frightened of being bathed and it took several months of gentle persuasion before she enjoyed it. She had major visual problems which had been untreated. The visual handicap increased her difficulties in other areas such as mobility. She could not name the days of the week nor count to ten. Her speech was very limited.

Subsequently, Agnes was found accommodation in the community with a carer who had another younger woman living with her who needed sheltered accommodation but who was more capable than Agnes. A follow-up assessment 15 months later found that Agnes had become part of the extended family of her carer, and a close friend of the other resident who enjoys sharing activities. Her vision remains limited but the correctable defects have been treated. Agnes has developed many self-care skills such as the ability to bath herself, make tea and help with household chores. Her numeracy and concept of time has improved, as has her confidence in social situations. She attends an Adult Training Centre daily, where she is learning to use transport. She enjoys choosing her own clothes and listening to music.

Agnes will probably always require sheltered accommodation but her ability to participate in life and express herself has been transformed.

She has not forgotten her mother and refers to her sometimes, particularly when watching TV which seems to have been an activity they shared most of the time. The memory does not distress her now.

Conclusions

- The recommendations of Strachan and Oswin[2, 3, 8] are a basis for developing guidelines for good practice.
- Non-verbal communication may be of particular relevance, and the resources of creative therapies such as art and drama may be helpful.
- Preparation for loss should be part of the teaching received at school and in further education. Teaching aids include a range of literature[9, 10, 11] and also a video[14].
- In addition to factual information, carers (both staff and parents) need an opportunity to discuss their own attitudes and ways of dealing with loss.
- It can be difficult for a family to discuss the future welfare of a handicapped member after the death of the main carer. Professional and voluntary organisations could provide a supportive forum in which to raise the issue. A solicitor with relevant experience can advise on the implications of the actions or omissions of the family.

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BOOK REVIEWS

WHEN DAD DIED
WHEN MUM DIED

Sheila Hollins and Lester Sireling. St George's Medical School, London, in association with Silent Books, Swavesey, Cambridge CB4 5RA. £6.95 each.

These are two short books which could help some people with a mental handicap or learning difficulties understand better the processes of dying and bereavement. The central theme of both stories is the same. The main character, Steve, is a young man who lives at home with his parents and sister. A parent becomes ill suddenly and is taken to hospital by ambulance. The parent is visited by the family during the illness but dies one night. The surviving parent tells the children and the following day they view the body in a coffin. There is a memorial service and later the family sort through the personal possessions of the dead person together and keep mementos. They remain a warm and caring family who after a period of