groups and general practitioners. Severe depression may require short-term medication of some kind.

For clients already in a 12-step programme (ideally with a sponsor), or receiving counselling from an alcohol services agency, the support they are already receiving may well go a long way to alleviating the alcohol problem in the grief situation.

Ending the therapy

During the last sessions, clients should be encouraged to set their own boundaries, accept that no-one is all-powerful, and that many things in life go beyond our control. Sometimes meditation or assertiveness courses help. By this time the bereaved person may be ready to go into some social group. Al-Anon, for instance, has a nationwide programme which encourages personal and telephone self-help.

Whatever the approach, recovery and healing can be a long, slow, exceedingly painful process. It is a journey during which many bereaved people find themselves and their lives completely changed.

Details of local groups of Alcoholics Anonymous or Emotions Anonymous can be obtained from a local Samaritans branch.For information about local Al-Anon groups (for families, friends and relatives of alcoholics) telephone 0171-403-0888

FORTHCOMING CONFERENCES

Death and Spirituality. 12–15 May 1996. Ontario, Canada. 14th King's College Conference on Death and Bereavement. Co-ordinator: Dr John D Morgan, King's College, 266 Epworth Avenue, London Ontario, Canada N6A 2M3. ☎ 519 432 7946.

Gone Forever Project: Helping Children and Young People to Understand and Cope with Bereavement and Loss. 13 July 1996. Sheffield, UK. Apply to: Conference and Short Course Centre, Sheffield Hallam University, Collegiate Crescent campus, Sheffield S10 2BP. ☎ 0114 253 2511.

Fourth International Conference on Children and Death. 5–8 April 1998. The Netherlands. Contact: Dr Z Zylicz, The Pallium Foundation, PO Box 90, 7010 AB Gaanderen, The Netherlands. ☎ 31 26 3645792

Death and people with learning disabilities:

Interventions to support clients and carers (part 1)

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The needs of people with learning disabilities who are bereaved have been acknowledged in the last decade. There is more understanding of ways to meet these needs. Carers need training and support when working with people who are dying or bereaved. This paper reviews the relevant literature, offers guidelines for practice and highlights areas for further development.

EVIDENCE OF GRIEVING

There is an extensive literature on dying and bereavement[1,2,3,4,5,6] but there has been little research into the needs of people with learning disabilities. Oswin[7,8] challenges the view that people with learning disabilities do not understand death and therefore could not grieve. She argues[9] that participating in the social response to death is both a right and a support in itself. People with learning disabilities will be bereaved and face death themselves and they may need assistance to interpret what is happening to them.

Emerson[10] found that some behavioural problems in people with learning disabilities had been precipitated by a bereavement. She reported that those caring for the person had minimised the significance of death or misunderstood the reactions to it. Disturbed behaviour such as aggression may be the only means of expression for some people with profound handicaps[11].

An early paper by Ray[12] describes two families in which the fathers died. Both mothers thought that their children would not understand and did not expect them to grieve. It became clear that the children's difficulties with understanding was not protective but added to their distress.

John, with Down's syndrome, was nine years old when his father died suddenly. Later his mother tried to discuss the loss with him but John became distressed and tried to injure himself. When a male visitor arrived John became excited, 'but when he looked at the man and realised it wasn't his daddy he just crumpled to the floor and started wailing'. On another occasion, on returning from a school trip, he ignored his mother waiting nearby and gazed around the car park saying 'Daddy'.

Bill was 16 years old when his father became ill. He saw his father's health deteriorating and visited him in hospital. Bill was staying in respite care when his father died and was unable to return

EDITOR'S NOTE

Adults who have learning disabilities (formerly described as adults with mental handicap) are a neglected group in relation to many services. In the days when they were hidden from public view in institutions, it was unlikely that volunteer bereavement counsellors would have been asked to help them. With care in the community a reality, not only are learning-disabled adults more likely to be living near us, their losses may be more difficult for them to bear when there are fewer people to share them. Fiona Cathcart has pioneered studies of how best to help these 'children in adults' bodies' to cope with the death of a loved one and points out that our knowledge of how children grieve, and their needs, can help us. We have already published an article by Cathcart[1] on this subject, and are delighted to reprint this comprehensive review article which enables us to share her wealth of experience in this field. Practitioners working with people with learning disabilities will find much to help them.

1. Cathcart F. Bereavement and mental handicap. *Bereavement Care* 1991; 1(1): 9-11.

home for 10 days because of a minor illness of his own. He became withdrawn when he could not find his father and wanted to visit him in hospital. His mother felt unable to explain death to him and told him his father had gone to work. Bill eventually stopped asking to visit his father but on a bus journey several weeks later, he became agitated when the hospital came in sight. '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'.

In contrast, another mother tried to explain to her daughter about her father's death. Despite this, it was some weeks before the young woman appeared to realise the loss[13]. She searched for her father as John and Bill had for theirs and called 'Daddy', which was the only speech she had. She refused to eat, accepted spoon-feeding reluctantly and vomited after meals. Her weight reduced from eight-and-half stone to just over four stone. She became listless, neglected her appearance and appears to have been severely depressed. Bradford does not describe any intervention apart from a stay in the hospital sick bay which was ineffective. She attributes her daughter's gradual recovery to time and possibly a stay at the hospital's holiday home.

It is clear from the accounts of these families that limited comprehension did not alleviate distress.

THE IMPACT OF DEATH IN AN INSTITUTION AND IN THE COMMUNITY

Reactions to bereavement in a large institution were explored by Strachan[14]. He studied 19 adults who had been resident for at least one year (mean 17 years). Nine were severely handicapped and 10 were moderately handicapped. All had been bereaved by the death of a close relative in the preceding year. He interviewed the nursing staff to assess the residents' reactions to the death. The nurses reported very little emotional response within the first 24 hours. Seven residents had been tearful but only one for any length of time. About half made remarks such as 'My Mummy died'. Five of the 19 seemed to understand the permanent nature of the loss, referring to the dead person and keeping mementos. One man became agitated and uncooperative and had a brief recurrence of mental illness. Another became irritable and noisy and uncharacteristically incontinent. Strachan comments that perhaps the residents' distress was undetected. One man described by staff as unaffected expressed anxiety to visitors about his future without his parents. Residents tended to lose contact with a sick relative during the terminal illness. The majority of the deaths were anticipated but only three people had attended the funeral.

Two-thirds of the group were told of the death by hospital staff. Strachan felt that this should have been done by a relative because the death was a family event. I have suggested elsewhere that each situation should be decided individually[15]. A familiar member of staff such as a key worker may be more skilled at communicating with the person than a relative who is less well known. The effect was different when a resident died. Other residents appeared subdued and tearful. It may be that these relationships were closer than the relationships with the family members who lived in the community. Strachan suggested that the nurses may also have been mourning and therefore more sensitive to the sadness of residents.

THE DEVELOPMENT OF THE CONCEPT OF DEATH

Several studies have suggested that the concept of death in adults with learning disabilities resembles the development of the concept of death in children[16,17]. The child's concept of death has been related to its level of cognitive development based on the stages proposed by Piaget. This framework was used by Kane[18] in her study of 122, middle-class American children of average intelligence. She identified 10 components of the death concept based on the previous literature (see Table 1).

The component of Personification was derived from Nagy's earlier work (cited in Kane[18]) but only four per cent of the children in Kane's study personified death in this way. The components were acquired gradually and there appeared to be three stages in the process, consistent with Piaget's model. Young children (three to six years) who had relevant experience of the death of others had significantly higher scores than inexperienced children of the same age. Experience was less relevant for older children.

Other authors warn against viewing age as the sole determinant of understanding illness and death. Bluebond-Langner[19] describes how terminally-ill children come to realise their fatal prognosis. This process is intrinsically linked to what they learn from staff behaviour and what they observe in their sick peers as well as the appearance of their own symptoms. She argues that a young child with the relevant experience could have a better understanding of the implications of its illness than an older child with the same prognosis.

The concept of death in people with learning disabilities

Bihm & Elliott[16] suggest the development of the concept of death in people with learning disabilities is related to their cognitive level defined by Piagetian tasks rather than chronological age. They assessed 79 young adults with mild learning disabilities (mean IQ 62, SD = 12). All attended vocational training programmes. Cognitive level was assessed by a series of tasks and understanding of death and dying was assessed by using questions, such as 'How can you tell when someone is dead?' Those people functioning at a pre-operational level had less understanding of death than those at the higher level of concrete operational functioning, for example, they were more likely to say the dead person could feel hot or cold.

The concept of death was explored in institutional residents with a wider range of ages and abilities by Lipe-Goodson & Goebel[17]. They interviewed 65 adults whose IQs ranged from 19–80 (mean IQ 40). The percentage of life lived in an institution varied from one to 99% (mean 58%). They were assessed on their understanding of the universality, irreversibility and inevitability of death. The group was divided by the median for: age (older 35–62 years; younger 17–33 years); IQ (19–34 IQ; 35–80 IQ); percentage of life spent in an institution (1–61%; 62–99%).

The authors predicted that living in an institution would shield residents from death. They assumed residents would be informed of a death only in their immediate family. A family death would not affect their daily routine by, for example, necessitating rehousing, financial changes or the demands of supporting someone through a terminal illness. Contrary to their expectations, length of stay in the institution did not affect the residents' performance on the assessment. One reason for this could be that the authors did not look at the

Table 1. Components of the concept of death (based on Kane[18])

1. Realisation: *the awareness of death, of the state of being dead or as an event which happens*
2. Separation: *the location of the dead, eg, in the sky, under the ground*
3. Immobility: *whether the dead are seen as active or inactive*
4. Irrevocability: *whether death is permanent or reversible*
5. Causality: *external or internal causes, eg, guns or a heart-attack*
6. Dysfunctionality: *the child's ideas about the body functions of the dead apart from the senses*
7. Universality: *does everyone die or are there exceptions?*
8. Insensitivity: *the dead may be considered totally or only partly insensate*
9. Appearance: *the dead may look the same as in life or appear different*
10. Personification: *death as a concrete person or thing, eg bogeyman, skeleton*

impact on non-family deaths. Residents would have experienced the death of fellow residents. The longer someone had lived in an institution the more important those relationships might be. Residents may have had a close relationship with members of staff and mourn staff deaths more than those of relatives. They did not examine recent life events in the group. It could be than one ward had experienced several deaths or that some individuals were admitted to the institution following the death of an elderly carer. The way in which deaths had been dealt with by staff will be an important variable. They concluded that the understanding of death in people with learning disabilities appeared to depend on age and, to a lesser extent, intelligence. Chronological age may reflect both experience and cognitive development. They concluded the development of understanding resembles that in children but that some adults with learning disabilities would never have a fully developed concept of death.

McEvoy[20] used a structured interview to assess the concept of death in 38 clients attending an adult day centre. The group was aged 20–50 years with two-thirds of the group below the age of 25 years. The majority lived at home with their families. The Index of Social Competence was used as an assessment measure. Those adults who were rated as more able on this measure had more understanding that death was irreversible and that body functions stopped at death. Those who agreed that they would die themselves one day appeared to have more understanding of other components of the concept. Death was seen as caused primarily by illness and disease but older clients were more likely to give natural causes as a reason. McEvoy noted an apparent lack of understanding of ageing and death as a natural part of the life-cycle. This may reflect the fact that some people with learning disabilities continue to be treated as children and are not encouraged to act, speak or dress in age-appropriate ways. Also, many social education groups end their courses with final sessions on sexuality and parenting. Discussion of major life-events is incomplete without an acknowledgement of death.

The participants were asked if they had known anyone who had died. The scores indicated that experience of bereavement in itself did not result in a better developed concept of death. Some studies[7,8,9] report that clients are given misleading or confusing information when they are bereaved. Being bereaved may not help someone understand death if the situation is not explained or if the person is excluded from the events surrounding the death. Possibly it is not the death but the meaning that is attributed to the experiences at that time that is important.

Dreams of people with learning disabilities have been another source of information regarding their concerns about death. Turner & Graffam[21] studied the dreams of clients attending a day centre. The group in this study varied considerably in IQ (WAIS 36–88 IQ; mean 58 IQ) and age (24–62 years; mean 31 years). Altogether 154 dreams concerning death were collated. There was no systematic attempt to assess their understanding or experience of death. A frequent theme was one in which the dead appeared, often in a menacing way, beckoning to the living to join them. Some reported recurring dreams of real traumatic events such as witnessing the accidental death of a relative. A disturbing feature of these dreams was the feeling of helplessness. The content of these dreams is similar to those reported by people without learning disabilities who suffer a traumatic bereavement. Other dreams were less distressing and had themes of reliving past happy occasions or the dead parent continuing to love and protect the dreamer despite their separation.

We will be publishing the second and final part of Fiona Cathcart's article in the Summer issue of Bereavement Care.

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