EDITORIAL

This issue carries papers and reviews which will be of especial interest to teachers. Jeffrey and Lansdown's paper highlights the little-appreciated fact that the staff and pupils of special schools for the physically handicapped pupil will have to cope with death more often than mainstream schools. But what he has to say will be of value to all teachers.

The number of books on the subject of childhood bereavement continues to increase, and we try to keep abreast of them and guide our readers to save their time. Some of the reviews published in this issue indicate that the market is becoming saturated but Rebecca Abrams has the double qualification of being a talented writer and having come through the fire of losing her father and her stepfather as a young adult, without the supports of school and home. She uses her talent as a writer to illuminate for us the particular problems of bereavement in this age group. Reading her article in this issue should whet your appetite for her book, also reviewed here (p. 22).

Finally, Vance compares parental responses to different types of early death in childhood—a paper which should be of great value to those counselling sorrowing parents.

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The Role of the Special School in the Care of the Dying Child

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It is acknowledged frequently that Western society is daunted by the prospect and event of childhood death; the Warnock Report[1] on special educational needs of children in Britain ignored the topic. The usual argument put forward to explain society's attitude is that the greatly reduced death-rate among young people has deprived most of us of the experience of coping. It is rare for children to learn about death as part of the school curriculum; however, in many special schools some knowledge is inevitable because of the greater likelihood of death among the children attending them. Of 108 schools for the delicate and physically handicapped in England and Wales replying to a questionnaire in 1979, all but 12 had experienced at least one death among pupils in the previous five years[2].

Teaching children in special schools about such a sensitive subject as death cannot use the same methods as teaching about trade-winds, or long multiplication. Life-and-death issues will arise when teaching about health, morals and religion, and they require a more open-ended response on the part of the teacher, enabling the children to talk, to listen to one another and to discuss the issues. As with sex education, group-teaching is not always appropriate, depending in part on the content of the session and in part on the characteristics of the pupils. A rule-of-thumb distinction is that the more powerfully emotive the topic, the less likely group work is to be useful. However, as with adults, some children gain strength from sharing deeply-felt emotions with others who have had similar experiences.

Taking advantage of events, such as the death of a grandparent or a pet, provides a more natural context for discussion than introducing the topic into an ordinary lesson. Teachers must listen for hidden questions or indirect statements from the children. A boy with cystic fibrosis is saying more than the mere statement 'Well, I've made it to my sixteenth birthday, then'. Some children will ask questions about their friends rather than themselves, or be even more transparent: 'You can die if you get ill, can't you?', or 'I hope I don't have to have a wheelchair like that one' —the latter from a boy with muscular dystrophy looking at a wheelchair designed for greatly reduced hand function.

Above all else, the special school has a duty to provide children with as satisfying a life as possible, particularly during the last few months. One approach is for the parents to take the child out of school altogether, for a series of holidays to places he would like to see. An alternative view is to keep him in school, but with a modified curriculum, emphasising creative work and trips to places of interest[3]. However, replies to our questionnaire showed that the majority of head-teachers keep all children to a single curriculum, preferring as far as possible to treat dying children as though they were healthy, but making allowances for increasing impairment in performance.

The reason for this apparently insensitive approach is that all teaching has a 'hidden curriculum' of underlying, unbroken messages which are transmitted to the children. They are in a special school, and already see themselves as different. The aim within the school is to minimise this difference, hence the refusal to single out a subgroup. Furthermore, it is notoriously easy for parents to overindulge a sick or handicapped child and to allow conduct that normally would not be tolerated, so impairing hitherto happy and mutually supportive relationships. Maintaining normal standards of behaviour, as well as normal lessons, counters this tendency. It is also possible that the more special kindness and consideration given to a child, the more worried

he will become about the seriousness of his condition, especially if adults are reluctant to discuss openly with him just how ill he is.

Bluebond-Langner[4] writes of the reassurance derived from normality when she describes a child's relief at being disciplined.

Many adults are reluctant to discuss imminent death with a child who is in that situation[5]. As a reason, some say they are uncertain about the level of children's conceptual development. As Wolff[6] has put it: 'The belief that children are "too young to understand" is often used to explain two common but contradictory approaches . . . children are either regarded as insensitive, unable to take in anything of what happens and therefore allowed to witness adult emotions and interactions without being given appropriate explanations; alternatively, they are endowed with exquisite sensitivity and vulnerability so that . . . facts . . . must be carefully hidden from them'. Other studies[7-10] suggested that the concept of death is complex, but is partly formed at an early age and complete by about nine years of age. This view was more or less borne out by the replies to our questionnaire: the teachers thought that six per cent of the children knew or probably knew about their own death at five years of age, rising to 30 per cent at 10 years and 62 per cent from 15 years onward. According to Parker and Mauger[11]: 'Like adults, it seems that many children know when they are dying. And also, like many adults, children may be unable to talk about it, or, more likely, they may be unable to find anyone who is willing and able to listen and to try to reassure them and to understand their fears and feelings. So children may die feeling lonely, with the people around them all knowing, yet pretending it is not going to happen'.

Many dying children do discover the fact, despite elaborate attempts at concealing it from them. Sometimes the truth 'falls from the sky', as with the boy with muscular dystrophy whose mother came into the room to see him watching the closing moments of a television programme on his disease and its implications. More often, the knowledge is realised gradually, for example from overheard conversations, from observation of other children and from newspaper articles.

It has been noted that children about to die rarely ask direct questions[4, 12] and avoid the topic of their own death, seemingly to protect their parents. Bluebond-Langner refers to the 'mutual pretence' that is evident at such times. A similar deception may exist between children and their teachers, but to an observably lesser degree, as children usually display more objectivity about their dying at school.

Teachers in special schools often spend a great deal of time in relaxed, easy conversation with their pupils. They may be able to discuss death with a dying child, either directly or obliquely, or at least indicate to the child that adults are aware of his worries. If teachers are to relieve some of the strain of the child's pretending with parents and others, they must have an agreed policy as to the best approach to the child and his friends. They should also try to discover the parents' views, and certainly establish with them what other support is available in the community from statutory or voluntary services, or from a church.

It is imperative that there is good communication between home, school and hospital in the period surrounding the death. Parents who meet understanding as well as sympathy at school are spared one extra burden. If home, school and hospital co-operate with one another, all three are able to work with increased confidence. It was encouraging to note that almost all the headmasters contacted in our survey reported that they had received adequate information on the child from medical sources; however, they were not always certain exactly what had been told to parents and children during the last few weeks. This may be a time when the school doctor can act as an effective intermediary between home, hospital and school.

Opinion was divided on whether it is appropriate to tell the friends of a dying child that the prognosis is so poor. In the event, many of the friends have already been told, or have guessed.

Very few children die in schools: most are at home or in hospital. Once the child has left school for what appears to be the last time, the value of a previously established communication network comes to be appreciated. In some cases a daily phone-call from the school is welcomed, but in others it is better to contact the health visitor, community nurse or family doctor. Some contact with the home is essential, for sooner or later the need will arise to tell the other children that one of their classmates has died.

There was more disagreement on this last point than any other in our survey. Some head-teachers deny that the child has died, saying, even in response to a direct question, that he has gone home or will not be returning to school. Others make no general announcement, but do answer individual questions truthfully. One or two mentioned that they tell the child's close friends before they tell anyone else, giving the friends an opportunity to be elsewhere when the general announcement is made. Two head-teachers tell children before they tell staff and thus avoid rumours spreading among the pupils. Many make a general announcement to the whole school and about half replied that they have no set policy and that they act according to the age of the particular child.

It was commonly noted that children do not react to a death in the same way as adults. Despite a common sense of loss, children's awareness of death is different from that of adults. For the adult, the death of a child involves more than the immediate loss: there is also the consciousness of a wasted life, the vulnerability of all children and the tragedy for the parents concerned. For younger children (under the age of eight or nine), however, the sense of loss of an apparently close friend may be less than expected; although children have close friendships, they are often short-lived. The young child may develop fantasies about death which need exploring. Statements by adults may well be misconstrued: a five- or six-year-old child, on being told that his dead mother was 'in Heaven' asked if Heaven was as far away as Brighton. The finality of death is hard for the younger child to comprehend fully. Another possible fantasy is that the child is in some way responsible for the death. Fantasies about death can develop at any time, of course, and exploration of ideas aroused by a death occurring some time previously may be important. However, children who have lost a close friend may well follow the classic phases of mourning and need the same help and comfort as the mourning adult.

Once children have been informed, a further group needs consideration: the parents of the child's friends. Such parents should be told during the day, so that they may absorb the information before their own child comes home, or in the case of a boarding-school, before the next home visit.

Parents usually welcome staff, and sometimes children, at the funeral but may be unsure about further contact with the school. If communication has been good, the school should have ascertained if the parents are informed about any

parents' support system in the neighbourhood. In some cases, they may already be part of that network. Some parents need no more than the assurance that they will be welcome at the school at any time; others appreciate an invitation to a specific event. A few may need gentle weaning from the school. However, all should be made to feel that the original support will continue beyond the time of the death.

There remain the marks of a child in school: his name on a list, his belongings, his books. There is no need for any of them to be whisked away; it is probably better to remove them gradually over a period of several weeks. Some memories can be consciously kept through photographs, and perhaps more powerfully, through casual conversations: 'Do you remember the day Billy brought his mouse to school and we couldn't catch it?'

A death always brings special sadness to a school. If it has been anticipated, however, it need not be devastating and may lead to psychological growth.

References

1. Committee of Enquiry into the Education of Handicapped Children and Young People (Great Britain), Chairman: HM Warnock. Special Educational Needs. London: HMSO, 1978.
2. Jeffrey P, Lansdown R. Survey of schools for the delicate and physically handicapped. Unpublished, 1979.
3. Oswin M. The role of education in helping the child with a potentially fatal disease. In: Burton L (ed). Care of the Child Facing Death. London: Routledge, Kegan & Paul, 1974.
4. Bluebond-Langner M. The Private Worlds of Dying Children. Princeton: Princeton University Press, 1978.
5. Lansdown R. More than Sympathy: The Everyday Needs of Sick and Handicapped Children and their Families. London: Tavistock Publications, 1980.
6. Wolfe S. Children Under Stress. Harmondsworth: Penguin Books, 1969.
7. Nagy M. The child's view of death. *Journal of Genetic Psychology* 1948; **73:** 3-27.
8. Anthony S. The Discovery of Death in Childhood and After. London: Allen Lane, 1971.
9. Kastenbaum R. Childhood: the kingdom where creatures die. *Journal of Clinical Child Psychology* 1974; **3:** 11-14.
10. Kane B. Children's concepts of death. *Journal of Genetic Psychology* 1979; **134:** 141-153.
11. Parker M, Mauger DC. Children with Cancer. London: Cassell, 1979.
12. Yudkin S. Children and death. *Lancet* 1967; **1:** 37-41.

Helping Teenagers and Young Adults Cope with the Death of a Parent

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The death of a parent is hard to bear at any age. Whatever the ages of the child and parent concerned, it will almost always result in a shift in self-perception, a reappraisal of the relationship with the deceased, and the often painful realisation that the possibilities for conciliation, reparation and explanation are now over. In my work interviewing and counselling teenagers and young adults[1], I have found that this age group is likely to face particular difficulties in coping with parental bereavement. In the short term, death and grief are incompatible with the many other demands and pressures on young people, and in the long-term, denied or unresolved grief can be the source of a range of problems in adult life.

Until recently the needs of young adults coping with a parent's death have gone relatively unheeded. Although literature on this kind of bereavement has been available for some years now in the United States, Britain has lagged behind. In her book, 'Aspects of Grief'[2], Jane Littlewood asserts that, 'despite the relative frequency of parental deaths, little research has been conducted regarding the impact of these deaths upon adult children.' Teenagers and people in their early twenties, in particular, fall between the two stools of research into child and adult bereavement. Yet they are an especially vulnerable group, who are even more than most in need of proper support, understanding and recognition in coping with death.

The death of a parent at this age represents not only the loss of a central figure in a young person's life, but also a fundamental part of their identity. A parent's death shatters both their world view and their innate sense of self, isolating them from friends and family, and making all the normal business of being young seem remote, disloyal (to the memory of the dead parent) and impossibly demanding.

An isolated group

Adequate support, whether formal or informal, is still singularly lacking for this age group and feelings of isolation and abandonment on the death of a parent are exacerbated by the absence of support and recognition.

Feelings of isolation are commonly expressed, isolation both from the peer group and from older adults with whom they come in contact, eg teachers, employers and relatives. A recurring theme is the painful loneliness these young people experience after the death of a parent. Many of them describe the feeling that there was no-one to talk to, that no-one would want to listen to what they needed to say, and that articulating their feelings was dangerous because it might lead to a greater degree of isolation. The tension between needing to talk and fearing the effects of expressing their grief preoccupies many young people. The reasons for the social isolation experienced by the young bereaved person are various. Incompatible notions in our society about what it is to be young and what it is to be bereaved certainly do not help, and a burgeoning youth culture has undoubtedly contributed to making this an awkward age group, isolated from younger children and older adults. Young people themselves are often wary of adults, and inclined to feel misunderstood or patronised by them.

In the context of a bereavement, older people, uncertain how to approach this age group, instead take refuge in the widespread misconception that the young are resilient and will soon 'get over it'. School teachers, college tutors and employers are also often reluctant to broach the subject, nervous about the overlap between personal and professional roles. Friends of their own age, however well-meaning, seldom have experi-