One person experienced intrusive imagery of the dead face and another slept with the light and radio on at night for several weeks. The CISD intervention helped staff to resolve their distress and plan with the residents how they wished to remember the dead man. A flowering bush for their small garden was chosen as a memorial which was poignant in view of their sadness that he was beginning to reveal concealed qualities.

RECOMMENDATIONS

Much pioneering earlier research has weak methodology and has not considered many important variables. Many studies have been limited to examining IQ, age and time spent in an institution. Bereavement outcome in the general population depends on many factors such as gender, social support, the nature of the relationship and the manner of the death[26]. These variables are likely to be important for people with learning disabilities too, although there has been no research to explore this.

The impact of a death on both clients and carers should be acknowledged by service managers and appropriate support given. The nature of the support will depend on the cultural and religious backgrounds of the individuals. There is potential for conflict when a client, relatives, keyworker and supervisor bring different traditions and ideas about the 'right' way to show feelings and express respect for the dead. Few training courses explore these issues but they need to be addressed if sensitive care is to be given[27].

There are complex legal and ethical decisions about treatment at the end of life. Some individuals prepare advanced directives to ensure their wishes about future treatment will be respected in the event of their becoming mentally incapacitated. There is continuing debate about the status of such documents in law. The dilemma is increased when the person has a learning disability. The debate about people with leaning disabilities and informed consent to treatment has focused on contraception and sterilisation. This needs to be extended to decide, for example, in what circumstances a person with a learning disability can refuse life-saving treatment. They may have had few opportunities to make choices about their lives and may find they have few choices in their death.

The difficulties people with learning disabilities may have in communicating pain and other symptoms can have tragic consequences[28]. Non-verbal ways of working with people with multiple handicaps need to be developed further. This would enable carers to understand more readily their physical and emotional needs in illness and death.

In conclusion, there is growing recognition that most, perhaps all, people with learning disabilities have some understanding of loss and many have some understanding of death. They grieve. Effective ways of supporting them in their own death and in grieving for the death of others are being developed. They have yet to be evaluated.

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Author's comment

*Dr Cathcart wishes to make two comments on the Editor's Note which accompanied Part 1 of this article (*Bereavement Care *1996;* ***15****(2): 7):* 'It is flattering to be described as pioneering this work but it would be wrong for me to accept this. I believe the credit should be given to Maureen Oswin to whom I refer in the article. The second comment concerns the parallel with children. Studies of the concept of death in children are useful in suggesting areas which a counsellor may consider when working with a bereaved person who has a learning disability, for example, causality or irrevocability. I did not wish to imply the person with a learning disability is a child in an adult's body. The parentheses around the phrase "children in adults' bodies" suggest it is a quote from the article but the phrase is not mine.'

LETTER TO THE EDITOR

Dear Editor

Last year in Bradford a woman, whose baby had died in the hospital maternity unit many years previously, discovered from the cemetery administration that it was possible to locate the plot where her baby had been buried. She was so relieved that she made this known through the local press. As a result many other parents, who had assumed that they would never know what had happened to the bodies of their babies, were also able to discover where they had been buried.

A local vicar arranged a commemoration service for these parents and relatives with the help of the bereavement care group of the local authority. As the recently retired hospital chaplain, I was invited to preach and suggested that, if they had not already done so, naming their baby, privately in their hearts, would bring comfort.

The Sister of the neonatal unit of the maternity department also spoke, apologising to all the parents who had not been encouraged to share their grief when their babies had died and explaining that the hospital staff had been not uncaring, but ignorant, of their needs. She described the current, more enlightened practice after a death and many ways in which babies can be remembered, and invited the parents present to allow the hospital to help now if they felt it would be appropriate.

Light refreshments were laid on afterwards so that the 200 or so present might talk to each other, and this was a further help to so many whose grief had been hidden for years.

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