KF REPORT

KFC 81/234

BEREAVEMENT AND MENTALLY HANDICAPPED PEOPLE

A discussion paper by Maureen Oswin

Dec 1981

King's Fund Centre,
126 Albert Street,
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King Edward's Hospital Fund for London is an independent charity founded in 1897 and incorporated by Act of Parliament. It seeks to encourage good practice and innovation in health care through research, experiment, education and direct grants.

The King's Fund Centre was established in 1963 to provide an information service and a forum for discussion of hospital problems and for the advancement of inquiry, experiment and the formation of new ideas. The Centre now has a broader interest in problems of health and related social care and its permanent accommodation in Camden Town has excellent facilities for conferences and meetings. Allied to the Centre's work is the Fund's Project Committee which sponsors work of an experimental nature.

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BEREAVEMENT AND MENTALLY HANDICAPPED PEOPLE: A Discussion document

Everyone's death is unique; even when it is expected it seems to those who mourn as if such a thing has never happened to anyone else before. Those who were close to the dead person feel the loss like a sickness. They may be devastated by their grief, having their sense of irretrievable loss mixed with other unexpected complicated emotions: guilt, anger, remorse, fear.

> 'No one ever told me that grief is so like fear, the same fluttering in the stomach, the same restlessness....(C S Lewis).*

For a while, those who mourn are special people, set apart, requiring respect and sympathy; allowances are made for them, they are expected to need time to adapt to the loss and the changes in life style that it will bring.

> 'The working out of a severe bereavement represents, as a personal crisis, a general principle of adaption to change. Life becomes unmanageable, because it has become meaningless. The context of purposes and attachments, to which events are referred for their interpretation, has been so badly disrupted by the loss that it at first seems irreparable. Not that the social environment itself has become unpredictable. The bereaved soon learns to understand the embarrassed overtures of condolences, the awkwardness that stilts old friendships, the changes in their status. There are practical affairs to settle in conventional ways. It is themselves they no longer understand, and hence they cannot foresee how to live to any purpose. They go through the motions of living, but they cannot see why it matters to them any more that they do this or that'. (Peter Marris).**

Ways of marking death have varied throughout history and according to current customs and religions. In Britain in the latter half of the twentieth century there has been a decline in the ceremony and formal display of mourning which was common in the nineteenth century. The decline has been variously explained as caused by a weakening in established religious influence, by people living much longer, by fewer people dying at home so that death has come to be regarded as a problem for the welfare state rather than for the family and neighbours. It is sometimes said that the twentieth century has developed as strong a taboo about death as the nineteenth century had about sex.

Irrespective of current 'fashions' in marking death, studies of bereavement suggest that mourning goes through recognised patterns(Parkes, Marris). Such studies are extremely valuable as they help in the understanding of the difficulties facing people who have experienced the death of a close relative or friend.

* Lewis, C S (1961) 'A Grief Observed', London, Faber and Faber.

** Marris, Peter (1974) 'Loss and Change' Institute of Community Studies.

As customs of mourning change and studies of human behaviour offer even more sophisticated explanations of our likely reactions to stress, perhaps the one fact about death which remains constant is the need for those who mourn to receive consideration. This paper looks at how people who are mentally handicapped are considered when they experience the death of somebody who has been close to them.

People who are mentally handicapped are sometimes thought of as a collective group who can easily be identified and labelled. It is still common to hear them described as 'childlike', 'dangerous', 'defenceless', 'uncontrollable', 'happy and friendly', 'unable to speak for themselves'. Such stereotyping is unjust. People who have mental handicaps are each very different. Their abilities vary, as do their background experiences, their family life, friends, education, interests, ideas, attitudes and ambitions. Their behaviour, like that of people who have been labelled 'mentally handicapped', will be influenced by their individual experiences. Unfortunately, grieving mentally handicapped people may lack consideration because society continues to have stereotyped ideas about them and subsequently may not appreciate that their emotional responses to death and their emotional needs when under stress are the same as the responses and needs of ordinary people.

> 'In the garden of a large mental handicap hospital, a thin, tall, middle-aged woman stood apart from the other women; she was holding a large brown knitted doll, and looked full of despair. The long legs of the doll were held over the woman's hips, her hands were clasped behind its back: she looked down onto its soft shapeless face and moved her lips, then lifted it and kissed it. The staff explained that this woman had only been living in the hospital for six months. She had come when both her elderly parents died within a few months of each other and there was nobody else to look after her. "It's about time she got over it" a member of staff said. "She won't do anything, and she won't be separated from that old doll. She brought that from home. We don't mind her having it of course, but it reminds her of home too much. She should be over all that by now, as she's got quite a lot of sense". It may take several years for anyone, handicapped or not, to cope with bereavement, yet the hospital staff were expecting that woman to have recovered only six months after having lost both her parents. One wonders how the death of parents is explained to mentally handicapped people, and what help they get in their grief and confusion'. (Oswin).*

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* Oswin, Maureen (1978) 'Holes in the Welfare Net', London, Bedford Square Press.

It would seem helpful to establish the following principles:

One: There is no reason to think that people who are mentally handicapped will not go through stages of mourning, as do other people.

Two: Mentally handicapped people have as much right as other people to be given consideration when their relatives and friends die.

Three: Each person who is mentally handicapped is an individual and will grieve as an individual; there is no reason to expect them to react in some particular way because they are mentally handicapped.

Four: Some people who are mentally handicapped have particular disabilities so they may need some special help when they become bereaved.

The following account of Miss G.....(here called merely 'Jane' to observe anonymity) illustrates how easy it may be for these four principles to be ignored:

Jane lived at home all her life, the only child of elderly parents. She had never been to school but started attending the local Adult Training Centre at the age of twenty-five. She was very happy there and made many friends. She could walk and dress herself with help, but had very limited understanding of the meaning of money, or how to use public transport or shops. She could make tea and toast, and liked to help her mother with cooking and housework. She had considerable speech problems and had developed a form of signing with her parents. This was not much like any known form of sign language but the staff at the ATC had learnt some of her signs and used these in conjunction with a picture board which her parents sent from home with her each day. When Jane was twenty-eight years old her father died. He had been ill for some months before his death and he died at home. His death was not a suprise to Jane and her mother, they had been looking after him together with the help of a daily nurse. When he died Jane saw him in his coffin and she went to the funeral and helped her mother to prepare the simple meal that the mourners had together afterwards. He mother explained to Jane that "Dad has gone to Jesus and will get better and we will see him again when we go to Jesus". On returning to the ATC a week later, Jane was encouraged to sign about what happened and she listened to the staff telling the other students about what had happened to her. She responded tearfully but bravely to the attention, the cuddles and sympathy of her friends amongst the staff and students. In her art class at the ATC she painted a series of pictures about her father's death and funeral, she made a vase in pottery classes to put on his grave, and for a few weeks the drama class in the ATC acted going to funerals.

For about six to nine months Jane suffered periods of depression and minor illnesses and she sometimes wanted to stay away from the Centre to be with her mother. But gradually she began to adapt to the changes which had been made in her life by the death of her father. She was helped by the loving support of her friends at the ATC and by her mother's always honest explanations about what had happened. She was also helped by the knowledge that she was a support to her mother in their struggle to mutually help each other live without the father.

Gradually Jane and her mother settled into a secure but rather restricted style of life. They went out much less often than before as her mother did not drive and the father's car was sold. Their social life tended to be centred around the activities connected with the local club for mentally handicapped people and the ATC. They would attend functions, open days, concerts, garden parties to do with the local mental handicap groups, usually being picked up by members who had cars.

One day soon after Jane's thirtieth birthday party her mother died very unexpectedly of a heart attack soon after she had seen Jane onto the ATC bus in the morning. The news was broken to her by the manager of the ATC, then a social worker took over as Jane was in a 'crisis situation'. The first problem was where she should go that night. One or two members of the ATC staff offered to accommodate her but the social worker advised them that this might be unwise and cause later complications as Jane was definately going to need long-term residential care somewhere and it would be best if she was placed permanently as soon as possible rather than start off by living with members of the ATC staff. A bed was found for her at the mental handicap hospital twenty miles away. The social worker went to her house and got a case of clothes for her but did not take Jane as she thought this would upset her. Later that day she took her from the ATC to the hospital. Jane had never been there before and knew nobody on the staff or what the place was for.

A distant relative organised the funeral but Jane did not go. This decided by the relative who had never met her and only knew about her as 'poor old Edward's defective daughter'. Over the next few weeks in the hospital Jane changes from being a secure, peaceful happy woman to one who was described in ward notes as 'anxious, sometimes aggressive and quarrelsome'. She 'refused to cooperate in the hospital's activity centre', she lost weight, pinched a nurse who tried to bath her and one night locked herself in the staff toilet. She was moved to two wards before she finally seemed to settle down into a pattern of rather withdrawn and passive behaviour.

She was visited by her friends from the ATC during the first few weeks that she was in the hospital and they felt worried about her appearance but were not sure what they could do to help her. They asked for a meeting with hospital staff to talk about her communication difficulties and the unusual form of signing she had used with her parents, but they were advised that she would be taught 'Makaton' and would be discouraged from using the peculiar signs she had learnt at home. When one of the ATC staff tried to talk with her about her mother's death she began to weep copiously and the following day the manager of the ATC had a phone call from the social worker to suggest that it was rather upsetting to have the past 'raked-up' just as she was beginning to settle.

The four principles of consideration referred to previously were not observed for Jane. She was suffering from extreme grief at the loss of her mother, her home and friends and nobody seemed to appreciate her normal feelings as a bereaved person. It was not that anybody was ever deliberately unkind, but the lack of local services that might have retained Jane in her familiar home district and the system of crisis admission to a hospital such a long distance away and the difficulties that the professionals had in identifying Jane's normal feelings resulted in emotional needs being overlooked. One or two of the staff felt that they wanted to help her, but they did not understand how they could; it seemed that nobody felt able to take the initiative and consider her feelings simply as a person who was mourning.

It was in a effort to draw attention to the ordinary and special needs of grieving mentally handicapped people that the King's Fund Bereavement Group was started in 1979. The initial meetings of the group were very informal and gave members opportunities to explore their personal feelings about death. Each member had fairly diverse philosophies and beliefs. Most had experienced the death of a close relative. All agreed that the grief of ordinary people was not yet fully recognised and that society still had a long way to go in developing a deeper understanding of grieving; all believed that mentally handicapped people were especially vulnerable and likely to have their grief unconsidered because they were mentally handicapped.

In March 1981 the group issued the King's Fund leaflet 'The Right to Grieve'. The leaflet did not set out to advise on how to help bereaved mentally handicapped people, it merely posed questions about some of the issues. This discussion paper is an attempt to expand on some of the questions which were asked in the leaflet.

SHARING

It is important that everyone is aware of what has happened so they can begin to help the person who is grieving. Unfortunately the staff at Day Centres, schools and hospitals sometimes get to know in a very haphazard way about the death of somebody who is close to the mentally handicapped person. There may be a delay in telling some members of staff and this can create distressing incidents for the mourning person. For example, if night staff in hostels or hospitals are not promptly informed about the death they may be puzzled and cross about the depressed or difficult behaviour of the mentally handicapped person at bedtime; or if volunteers or the escorts on hospital or hostel buses are not informed they may make jocular remarks about "what will your mum say if she saw you pulling a sad face like that".

In some large institutions it is possible for a grieving person to be taken to the recreation hall and encouraged to dance and sing by volunteers who have not been informed about their state of grief. If everyone knows what has happened it may prevent the insensitive jollying-along of grieving persons.

Some members of staff may feel that they do not need to know any specific details about the mentally handicapped person's bereavement in order to be able to help, but others may feel more useful if they are given details about the dead relative or friend so they can talk more freely about them to the mentally handicapped person.

A crucial matter is exactly how the mentally handicapped person gets to know about the death; who tells them and where and in what terms? It would seem important that the person who actually breaks the news maintains some supportive contact with the mourning person in the following weeks but this may not always happen. When Jane's father died she had her mother to support her and she had her regular and happy relationships at the ATC each day, and she also had a meaningful role in supporting her mother. Whenher mother died she was given the news by the kind and familiar staff at the ATC who had known both her parents well, but then almost immediately she lost contact with them because of her removal to the distant mental handicap hospital where there was nobody who knew her. Jane had no opportunities to share her grief with people who were familiar with her and her parents. At the same time as losing her mother she also lost her home, her friends, her work and neighbourhood, and had to adjust to a total re-structuring of her life. Such a situation would tax the emotional strength of anybody so it is not suprising that Jane, with the added complications of mental handicap and speech disabilities, sank under the strain and became overwhelmed by grief and loneliness. What was Jane to do about the 'fear' referred to so movingly by C S Lewis as he described his grief at the death of his wife? She might have been helped if she had known that her mourning was shared by others. Sharing might have been in the form of attending the funeral with the comforting friend or member of staff, visiting the grave, buying flowers together, making a vase in pottery class as she did for her father's grave.

One of the special problems facing mentally handicapped people when they are mourning is that whereas ordinary people are usually able to exercise choice regarding their activities and who will support them in their grief, mentally handicapped persons may be suddenly cut off from all their familiar friends in the neighbourhood through being removed to an unfamiliar residential facility some way away from their homes. This is particularly true of people like Jane, who have always lived with ageing parents and have never been away from home. Jane not only shared her parents' home, she also shared their friends and activities, so when they were dead she also lost her social life. There was nobody familiar to share anything with anymore.

If there is no possibility of somebody previously known to the family sharing the mentally handicapped person's grief, then one particular member of the staff might be specially assigned to give special support in the first few months of the person's loss.

Sharing can mean enabling a continuity between the old life and the new. It can mean respecting the person's past life, trying to keep to old routines as far as possible, being aware of old memories and letting the mentally handicapped person know that these memories are known about and thought important.

In one hostel the sharing took the form of bringing a piece of furniture from the family home; for one person this was an ancient fireside chair which had been much loved by the dead father. The mentally handicapped adult son installed the chair in his room at the hostel and it helped him to retain important memories of his father and provided a link between his old life and his new.

Sharing may also mean obtaining full information about the grieving person's lifesyle before the loss occured so that there is a follow-over of ways of doing things. In one hostel there was a firework display each November 5th, but one year a newly arrived recently bereaved person refused to go to it and showed unusual signs of aggression and grief when the staff tried to persuade him. By his signing and gradually discovered that when he had had fireworks at home he had not gone outside himself, but had stayed indoors and watched his mother holding sparklers outside. This was done by the staff, and he watched from his room and settled down contentedly to a firework display just like his mother used to do it.

REACTING

It is important to remember that people respond to bereavement in different ways. However, at the same time, there are certain recognisable reactions to expect. Depression, loss of sleep, loss of appetite, anger, fear, are normal reactions to the death of a close relative or friend. The literature on bereavement suggests that mourning people go through patterns of adjusting to the loss. There is no reason to think that the reactions of mentally handicapped persons will be different from those of other people just because they are mentally handicapped. It would seem important for staff of Adult Training Centres, hostels and hospitals to be aware of current literature on bereavement and the particular groups concerned for the counselling of bereaved persons (such as CRUSE, Compassionate Friends) and have opportunities to attend conferences organised by such specialist groups (see Appendix One). In this way they may be helped to develop more awareness of normally expected reactions to loss and thus obtain insight into the effects of bereavement.

HELPING

It is very important to remember that the necessary support can come from a variety of people. Affectionate attachment and being 'on the spot' when needed might be more important than professional expertise: a member of the hospital's domestic staff who is always there at breakfast time and bedtime could be more helpful than a social worker who may be professionally trained in counselling but does not know the mentally handicapped person and can only visit the ward once a month. The counselling skills of social workers may not, of course, be superseded by less well qualified members of staff, but the frequent and regular support of more easily available staff may provide the most immediate form of help.

How much the staff feel able to talk with any intimacy to the grieving person will depend on the individuals concerned, but it would seem important for staff to find opportunities to talk about it in a way that might provide comfort, explanation and reassurance to the grieving person. This may well mean being aware of the person's familiar background and life-style (as referred to above) so that there can be a continuance of family traditions. There should also be a maintenance of family beliefs. If a mentally handicapped person has been brought up to believe that death means 'going to Jesus' it is important for this to be respected and continued. They will not feel much comfort if their statement that "Mum has gone to live with Jesus" is promptly contradicted by a professional whose personal philosophy of life makes them disagree with this view. Religious or secular beliefs should be respected even if these may conflict with staff beliefs.

The language they use to describe what has happened to them ('gone to heaven') should also be respected, as this may provide them with a way of making sense of their loss.

Some members of staff will find the mentally handicapped person's situation so painful that they will feel quite unable to help and therefore avoid contact with them or talking about it. This is one understandable reaction and no member of staff can or should be forced into a distressing situation in talking about the death, but it is important that somebody does it and is known to do so, otherwise there may be a complete silence about the happening and thus a denial of the grieving person's feelings. Staff attachment (as referred to on page 6 and this page) would be one way of ensuring that this does not occur. Although the attached member of staff may be almost casually self-appointed through feeling an affinity with the mourning person. It might be desirable for a senior member of the staff to make sure that such attachments are actually taking place so that the needs of the mourning person do not fall through the net by everybody thinking that somebody else is giving the help when in fact nobody is doing so.

How members of staff talk about the death of a relative or friend is very important. They may look at photographs together, go to the funeral, remember anniversaries by visiting the grave. The ways of sharing grief are varied and some were briefly mentioned on pages 6 and 7.

There may, however, be special problems caused by some aspect of the person's handicap, which will make it extra difficult for them to comprehend what has happened except perhaps in terms of total loss and separation from a loved familiar figure. Here one thinks especially of very severely multiply handicapped persons who, in addition to being mentally handicapped, may also be disabled by cerebral palsy, unable to move about, blind, deaf and without language. These profoundly handicapped persons may find it very difficult indeed to understand verbal explanations about their loss. Their main comfort may be through being held and comforted by physical touch. It may be possible to help them if some item of their past life that has some special meaning for them is retained, eg a blanket, a chair, a way of cooking something, a way of feeding them or holding them, a catchphrase always said at bathtime or bedtime. Some very severely handicapped people may have lived restricted lives in small rooms for many years, perhaps cushioned on one settee, their lives bounded by the security of the smell, touch, sounds occuring in one familiar small house where there is just one parent doing all the caring. All this will disappear when that parent dies and the very dependent mentally handicapped person enters a large hostel or hospital and has to live in a bright airy room, lying on plastic rather than familiar grubby upholstery, hearing unfamiliar echoes thrown back by high bare walls and having strange food to eat.

The physical and emotional trauma of such changes should be acknowledged, and ways should be sought to ease their sudden deprivations of the familiar. The staff of one hospital referred to how distressed they felt when a profoundly handicapped person was admitted after her mother died and she refused to eat and they feared she would pine away. The only comfort she seemed to get was through cuddling. But after a few weeks they discovered that she was most content in the kitchen amongst the smells of cooking and she particularly liked to suck pieces of toast and Marmite . They believed that she had probably spent a great deal of her time in the kitchen with her mother so they tried to give her similar opportunities by letting her sit in her wheel chair in the ward kitchen whenever possible.

Talking with the mentally handicapped person about death may pose difficulties for staff, as the concept of death is difficult for anybody to grasp, whether they are very intelligent or have some degree of mental handicap. A sister in one hospital said "I am afraid it's the blind leading the blind. I'm not at all sure about my own concept of death, and when I talk to mentally handicapped persons about it I don't feel that I'm offering them much out of my own muddled feelings at all".

When a mentally handicapped person who lives in a hostel or hospital becomes ill and dies it is sometimes arranged for the other residents to go to the service and funeral. But sometimes the death is hushed-up because the staff feel they should shield the other residents from knowing what had happened. A young charge nurse in one hospital referred to the need perhaps for the other mentally handicapped residents to see the body of their friend who has died. "We staff are maybe so busy when a resident dies, that we forget all about the other residents for a while... ....maybe we should think of some way to involve them more during the moments immediately following the death". How this might be done would depend on the feelings of staff and residents, but rather than thinking of sheilding them from the event it might be helpful to ensure that some simple group ceremony takes place, such as placing flowers besides the body, saying a prayer, or reading a poem or playing a favourite tune to mark the person's death. In this way, the other residents have the occasion marked and through their awareness the uncertainty and secrecy and fear of the occurrance may be lessened.

CARING

Giving support is not easy. A discussion with other people can be helpful. Although managing to give considerable support some staff may feel quite inadequate about their ability to cope. A social worker said "I had to admit her to hospital as an emergency when her mother died. I went back the next day to see her. She cried and I told her that her mother had gone to heaven. I knew that was what her mother said when people died. Later on I took one of her mother's dresses to the hospital and she sat crying and stroking it for a long time and I sat with her. I wonder whether I did right, and I still do not know. But it seemed wrong to suddenly whisk her away from her past life and never let her see anything familiar again or try to explain what had happened to her. She might have thought that her mother had sent her away because she did not want her anymore. She was very sensible and I think that she gradually believed what I was telling her and knew I was trying to help her and share it all with her as much as I could. But I'm still not sure whether I handled the situation properly".

Staff have many unanswered questions to worry them. Do they talk about death or not? How often? When should they encourage crying, and when should it be discouraged. Should it ever be discouraged? Does it matter if they cry themselves as they try to help the grieving mentally handicapped person? How do they cope with their own feelings if the distress of the mentally handicapped person also brings back their own painful memories about a bereavement? They may be particularly worried about whether they should remain detached from the grief they witness. "We cried together. It was sad, I didn't care. The nursing officer came in and saw me crying and seemed to think I had got too emotionally involved, but why should I be ashamed of my tears?" said a sister.

One way of helping awareness of a mentally handicapped person's grief and one way of helping to support staff who are trying to meet their needs might be for staff to form a 'bereavement group' in the residential facility. This would be a group of staff and relatives meeting informally on occasions for discussion about death and how individual mentally handicapped persons may be supported through periods of mourning.

The members of the 'bereavement group' would not consist of any one particular group of professionals and would not regard themselves as 'the experts' but would be made up of interested persons who have a genuine concern to help bereaved mentally handicapped persons and wish to formulate aims of helping, and ways in which support may be achieved. One function of the group would be to keep all staff informed of a newly bereaved mentally handicapped person; by merely communicating this information to all who are in contact with the person could be helpful, so that all are aware of the situation. The group might also invite relevant people to speak to them occasionally, such as a local member of CRUSE, and see that helpful literature is distributed to staff.

FAMILIES

A parent in a discussion about bereavement said "what I'd like to be sure of is that my son will have a chance to make a close relationship with somebody when I am no longer here, that is the most important thing to me".

Each family will have its own thoughts about how much their mentally handicapped member should know or not know about the future death of close relatives and the changes that are likely to occur after this happens. Some parents prepare their sons and daughters by talking about the event and letting them stay away in a hostel for short-term care as they get older so that they experience being independent and have an opportunity to develop interests of their own. Some parents make sure that their mentally handicapped sons and daughters move out of the family home when reaching adulthood, and have a new home in a hostel or flat whilst the parents are still alive, in the same way as most ordinary young persons do. Other parents, however, get depressed by the lack of appropriate residential facilities in their neighbourhood and say "We live each day as it comes and refuse to think about the future". (Wertheimer's study of older parents and their adult mentally handicapped sons and daughters vividly illustrates the particular problems created by poor residential services).*

Some parents, although there may be appropriate local facilities to which their sons and daughters could move, tend to be reluctant to let them leave the family home and do not believe they can make a life of their own. They find it difficult to accept that their mentally handicapped sons and daughters are not children forever.

*Wertheimer, Alison (1981) 'Living for the Present', Campaign for Mentally Handicapped People, Enquiry Paper No9.

It is extra hard for these young mentally handicapped adults to make adjustments when their parents die, because they have always lived at home and shared their parents' lives and friends and made no lives for themselves. Perhaps Jane (referred to earlier) may have adapted less painfully to her mother's death if she had had an experience of being away from home earlier whilst her mother was still alive.

It is understandable if parents are afraid about the future and try to ignore it, but some preparation for change and making a home of their own away from their parents, either in a hostel or sharing a flat, would be one way of lessening the massive stress that is likely to occur when parents die and leave a young mentally handicapped adult who has never been away from home before.

As well as having experience of living away from the parents, preparation may be through discussions held at schools, Adult Training Centres or Clubs, about death and the changes it brings to people's lives. The death of pets or animals looked after in school or the Adult Training Centre may help the person to develop some concept of death. The sharing of other peoples' grief, learning to be sensitive to the sadness of neighbours, staff and friends who are mourning, being aware of one's responsibilities in offering comfort to others, can be a preparation for that time when one is personally experiencing the death of a close relative or friend.

Conclusions

It is extremely difficult for anybody, whether they are handicapped or not, to get any real understanding about death. The discussion paper cannot offer any firm conclusion except to say that grief is normal and due consideration must be given to mentally handicapped people who are grieving. The following questions, which were asked in the leaflet 'The Right to Grieve', may provide a helpful framework for further discussion and action.

Sharing

It is important that everyone is aware of what has happened.
How do you get to know about the death of somebody close to a mentally handicapped person?
How does the mentally handicapped person get to know?
How much detail of the circumstances do you think you need to know in order to help?

Reacting

It is important to remember that people respond in different ways.
Are you aware of possible reactions to bereavement?
Would you expect a person who is mentally handicapped to react in any different way?

Helping

It is important to recognise that the necessary support can come from a variety of people.
How do you and the mentally handicapped person talk together about death?
Do you talk about it?
Do you feel personally able to help?
Do you think that the person you are trying to help might have additional problems in understanding what had happened?
Will he or she need any special help?

Caring

Giving support and sympathy is not easy. A discussion with other people can be helpful.
What are your feelings and what additional help is available to you?
What sort of help would you like?
Have you talked about this problem to other people so that you can all try to understand a bereaved person's grief in a helpful manner.
Perhaps an informal bereavement support group, made up of interested and sympathetic people, would be valuable. Have you thought how such an informal group might be started amongst staff, families and friends?

APPENDIX ONE

Recommended further reading

Lewis, C S (1961) 'A Grief Observed', London, Faber and Faber.

> A series of reflections by a husband upon the death of his wife after a long and painful illness.

Parkes, Colin Murray (1972) 'Bereavement', London, Tavistock Publications

> A book based on twelve years research into the feelings and reactions of widows, describing the typical manifestations of grief, attempts to mitigate it and the gradual reconstruction of the individual's world as the grief declines.

Oswin, Maureen (1978) 'Holes in the Welfare Net', London, Bedford Square Press

> A study of individuals who have various handicaps and the ways in which they and their families find their problems are increased by deficiencies in the statutory services.

Picus, Lily (1976) 'Death in the Family'. London, Faber and Faber.

> A study of bereavement and its effect on relationships within families, containing also many personal memories about people whom the author came to know during her work as a social worker, psychotherapist and teacher.

Cook, David (1978) 'Walter', Penguin, 1980.

> A novel about a family, mostly centred on the life of the mentally handicapped son, his employment in Woolworths stores, his interest in his father's pigeon breeding and what happens to him when his parents die and his style of life collapses around him.

Marris, Peter (1974) 'Loss and Change', Institute of Community Studies, London, Routledge and Kegan Paul.

> Looks at how in bereavement we struggle to come to terms with loss and reconstruct a meaningful life in a new way which takes account of that loss. Peter Marris shows that the same process occurs in other situations of loss such as moving house, or changing jobs.

Wertheimer, Alison (1982) 'Living for the Present', London, Campaign for Mentally Handicapped People. CMH Enquiry Paper No9.

> Report of a study undertaken through interviews with older parents with a mentally handicapped son or daughter living at home; looks at life within the family and at social life; use of statutory and voluntary services; plans for the future. Makes general and practical recommendations for future service.

A helpful film:

'Best Boy'

Film maker Ira Wohl made this moving film on the life of his mentally handicapped cousin Philly who spent his life at home with his elderly parents. This film shows the way his life changes when his father dies and how he develops and grows when he moves away from his mother to a group home. USA. 1979.

This film is available for hire from: Concord Film Council Ltd, 201 Felixstowe Road, Ipswich, Suffolk IP3 9BJ.

APPENDIX TWO

Some helpful addresses:

1. CRUSE: The National Organisation for the Widowed and their Children.
at Cruse House, 126 Sheen Road, Richmond, Surrey. Telephone: 01 940 4818.

2. The Compassionate Friends. 25 Kingsdown Parade, Bristol. Telephone 0272 47316
An international organisation of bereaved parents offering friendship and understanding to other bereaved parents.

3. The London Bereavement Projects Group, London Voluntary Services Council,
68 Charlton Street, London NW1. (The group meets to discuss problems involved in the area of counselling bereaved persons).

APPENDIX THREE

The bereavement group was started in 1979 by Joyce Knowles of Castle Priory College and Maureen Oswin of Thomas Coram Research Unit. The initial meetings were held at the Spastics Society in Fitzroy Square and the first small group consisted of the following members:

Elisabeth Goffe, Compassionate Friends

Julian Hodgson, National Council of Voluntary Organisations

Joyce Knowles, Castle Priory College, Spastics Society

Maureen Oswin, Thomas Coram Research Unit

Val Rosambeau, Spastics Society

James Ross, Royal Society for Mentally Handicapped Children and Adults

Joan Rush, King's Fund Centre

Philippa Russell, Voluntary Council for Handicapped Children

In 1980 the group expanded and then began to meet at the King's Fund Centre, from where the leaflet 'The Right to Grieve' was published in 1981.

The later members of the group were:

Ruth Bradford, Castle Priory College

John Cooke, Northampton Social Services Department

Audrey Cruickshank, Central Council for the Education and Training of Social Workers

Una Duerdin, Calderstones Hospital, Blackburn

Pauline Fairbrother, Royal Society for Mentally Handicapped Children and Adults.

Sheila Kidd, Gloucester Centre, Peterborough

Madge Mathews, Sutton and West Merton Health District

Elizabeth Marshall, Family and Community Service Department, Sheffield

Jean Satterthwaite, Meanwood Park Hospital, Leeds

Leslie Turner, Princess Marina Hospital, Northampton

Alison Wertheimer, Campaign for Mentally Handicapped People

During 1979-81 meetings were also held at two hospitals and two Adult Training Centres and acknowledgements are made for help and cooperation of the residents, staff and relatives of the Princess Marina Hospital, Northampton and Meanwood Park Hospital Leeds and the students of Kingston Adult Training Centre (Manager - Ken Foggan) and Mitcham Adult Training Centre (Manager - Jan Malinowski) and Edna Wallace of the Gardiner Hill Unit and Morag Plank who attended the Mitcham ATC meetings.

In writing this discussion paper Maureen Oswin acknowledges the help and ideas which were given during the meetings by all the people listed above; but she takes ultimate responsibility for the views expressed in the paper as well as any omissions.

in 1982 Maureen Oswin is to begin an eighteen-month research study into how mentally handicapped persons are helped when they become bereaved; she would be pleased to hear from anyone who is interested in the study or has any views to express or stories to tell. The study is being funded by the Rowntree Trust and will be undertaken from the Thomas Coram Research Unit. Please contact: Maureen Oswin, c/o Sandra Stone, (Bereavement Project Secretary), Thomas Coram Research Unit, 41 Brunswick Square, London WC1 (Telephone: 01-278 2424).