

# **The management of bereavement in services for people with autism**

(Code of Practice Procedures, Document 3)

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## **Introduction - Section 5**

'There is no growth without pain and conflict and no loss that cannot lead to gain.'

(Lily Pincus, 1961)

### **1 Introduction**

Until recently, people with learning disabilities have been denied their right to grieve, on the mistaken assumption that they had no capacity to do so. This process of dehumanisation has been made all the more poignant by the movement toward advocating their rights in other areas (Kitching, 1987). Recognition both of their right

and their capacity to grieve has led to a realisation that staff caring for people with learning disabilities should be trained to enable them, when they suffer loss, to complete the tasks of grieving in their own way and in their own time.

## **2 Purpose of this document**

The purpose of this document is to lay down guidelines to enable staff in services for people with autism to offer confident, informed and sensitive support to those in their care in the event of bereavement.

There is a great deal of easily accessible literature on bereavement, and it is strongly recommended that staff familiarise themselves with the common reactions to bereavement by referring to it. (See Appendix 1, References, and Useful Addresses) This document will draw attention to the responses to bereavement of people with autism, and will suggest ways in which staff can train themselves in the management of bereavement, both in its practical aspects and in offering support to clients, staff and others who might be affected by bereavements occurring in services for people with autism.

It cannot be over-emphasized that because of individual reactions to bereavement, this document cannot be prescriptive in those aspects relating to supporting people with autism undergoing the grieving process. It can only suggest measures which can be adapted to individuals or from which a choice can be made.

## **3 Responses to bereavement**

Bereavement is defined as 'the loss of something that is precious' (*Good Grief* (2), 1989). It usually refers to the death of someone close, but can include a significant change in one's life or the loss of a significant object. All these life events may evoke a grieving process in clients, and staff should be aware of this. The most catastrophic loss, however, is usually brought about by the death of a person.

Studies of people with learning disabilities have shown that of those who for no apparent reason suddenly presented with emotional and management difficulties, approximately half had experienced the death or loss of someone close prior to the onset of symptoms (Emerson, 1977). Similar results were shown in a study of admissions to an acute psychiatric ward of people with learning disabilities suffering from neurosis (Day, 1985). A limited cognitive capacity does not indicate a limited emotional capacity (Sireling quoted in Kitching, 1987).

Whether or not they are learning disabled, people react individually to grief, but most people share certain reactions (Appendix I). Because people with autism are handicapped in their social interactions, it might be concluded that they do not form attachments to other people, and are therefore insulated from the grieving process. In fact, they can be deeply affected by the death of someone close, as illustrated by the evidence collected in discussions with parents and staff and by means of a questionnaire, summarised in Appendix II.

The examples available of people with autism who have achieved a successful resolution of grief are those who have received skilled support either from family members or members of staff.

On the basis of the evidence now available, five further conclusions can be reached:

- all people with autism react individually to bereavement
- they may share the 'common reactions to bereavement' and may be affected by the major determinants of reactions to grief
- they may undergo reactions similar to those of bereaved children and young people
- the problems and reactions of other bereaved people with learning disabilities may also be experienced by people with autism
- the grieving processes of people with autism are profoundly affected by their disabilities

It follows that the training resources and publications relating to bereavement in children and people with learning disabilities can be particularly helpful to those caring for people with autism (see References).

#### **4 The process of grieving**

The common reactions to grief are described in Appendix 1. Any or all of these reactions may be experienced by bereaved people. Many experts view grief as a process, with identifiable stages:

SHOCK, numbness, denial

DESPAIR, turmoil, acute grieving, including:

- anger
- guilt
- anxiety, fear, panic
- depression
- pain, appetite disturbance, breathlessness, illness
- more than usual need for sleep, sleeplessness, hyperactivity
- nightmares
- regression, loss of skills

RECOVERY, acceptance, resolution of grief.

These concepts are helpful, provided it is understood that people do not experience an orderly progression from one stage to the other. It is preferable to view these stages as responses which overlap and merge with each other (A T Carr, 1988). The shock/denial stage may last for hours or weeks. The other stages last longer and have no time limit. Normally, mourning the loss of a close relationship takes a year and may take as long as two years.

Acceptance and recovery do not imply that the grief is 'over'. It can be felt throughout life, sometimes as a stab of pain, but also in the form of a memory of shared

experience. **Anniversaries** are particularly difficult, the date of death, birthdays, Christmas and other festivals which might have been shared with the deceased.

**Unresolved or complicated grief** occurs when the bereaved has failed fully to experience the stages of grief or to have performed the tasks of mourning identified by J William Worden (1988):

- to accept the reality of loss
- to experience the pain of grief
- to adjust to an environment in which the deceased is missing
- to effect an emotional withdrawal from the deceased and invest in other relationships.

## **5 Determinants of responses to grief**

The major determinants of the intensity and duration of responses to grief, common to all people suffering from bereavement are described as follows:

**1 Who the deceased was**, the closeness of the relationship to the bereaved.

**2 The nature of the attachment**, strength, security, ambivalence of the relationship.

**3 Mode of death**, whether it occurred suddenly or with advance warning. It is usually easier to accept the death of a person ripe in years than that of a young person. Natural deaths are more easily accepted than accidental deaths. Suicides and homicides are particularly difficult to accept.

**4 Historical antecedents**, the bereaved's previous experiences of grieving. The irresolution of a previous death may affect the reactions to a subsequent one.

Those with a history of depression will have difficulty in coping with bereavement.

**5 Personality of the bereaved**, age and sex of the person, whether they have difficulty in expressing themselves, how they handle anxiety and stress.

**6 Ethnic and religious background** (Worden, 1988.)

Staff wishing to offer support to a bereaved client with autism will wish to bear these in mind and brief themselves accordingly. They need also to be aware of how the disabilities of autism and the client's position on the 'autistic continuum' can affect their grieving process. These factors will be discussed in various contexts in this document, but it should be pointed out here that the wide variation in the capabilities of people with autism introduces an additional complexity into the functions of staff offering support to bereaved clients. For example, a client at the able end of the continuum might require detailed explanations and opportunities to explore their own concepts of death and after-life beliefs. The majority of clients - those in the middle of the range - would probably derive most comfort from simple, factual, directive language. Those at the lower end of the continuum might be confused by any but the minimum of information. Accordingly, staff must be prepared to respond with flexibility, depending on the capacities of the individual.

Specific grief reactions of people with autism are described in Appendix II. It is important to bear these in mind, as they may help staff to interpret the reactions of those in their care.

## **6 Bereavement in services for people with autism**

Bereavement in services for people with autism may take the following forms:

- 1 Losses other than death affecting individual clients
- 2 Loss of a family member or someone close to them by individual clients
- 3 Death of clients
- 4 Death of staff members

The greater part of this document is concerned with 2, but most of the suggestions made in this context can apply to 3 and 4 which are discussed more briefly, but which can have a profound impact on clients and staff.

## **7 Preparation for bereavement management: objectives**

Preparation for the management of loss and bereavement in services for people with autism should have the following objectives:

- 1 To ensure that staff are aware of the grieving process
- 2 To enable staff to undertake the practical arrangements surrounding bereavement
- 3 To enable staff to prepare clients for loss and bereavement
- 4 To enable staff to offer help to parents\* in preparing for their own deaths as they will affect their family member with autism
- 5 To enable staff to help siblings or family friends to become more involved in the caring role
- 6 To identify the need of individual clients for 'befrienders' and citizen advocates and to enable staff to take the appropriate action
- 7 To ensure that clients are supported during their grieving by designated members of staff who understand the grieving process
- 8 To enable staff to offer support to bereaved clients, including making the rituals of death more meaningful for them, supporting them in their own way of grieving, and in formulating their own concepts of death and after-life beliefs.
- 9 To ensure that staff receive the support they need both in their management of clients' bereavement and in their own grieving for clients and colleagues

10 To ensure that surviving family members are offered help in understanding or at least in coming to terms with the reactions of bereaved clients

11 To ensure that surviving family members of deceased clients are offered support.

This document suggests ways for meeting these objectives on the understanding that each bereavement is unique and that staff responsible for the management of bereavement will need to decide which measures are appropriate in any particular circumstance.

\* Throughout this document when the word 'parent' is used, this refers to a 'significant family member or friend', if there is no living or interested parent.

## **8 Formation of Bereavement Support Groups**

It is strongly advised that Bereavement Support Groups be set up in services for adults with autism with the following objectives:

- training staff to prepare clients for losses encountered in everyday life and the deaths of people close to them
- training staff for the management of bereavement
- preparing staff for undertaking the practical arrangements surrounding bereavement
- ensuring that clients, clients' families and staff receive the support they need.

In order to meet these objectives, the Bereavement Support Group members will wish first of all to train themselves as suggested in this document and to bear in mind the objectives for the preparation for loss and bereavement management as set out in paragraph 7 above.

Membership of a Bereavement Support Group might be drawn from the following:

- members of staff
- members of the local clergy
- members of CRUSE, The Society of Compassionate Friends, The Samaritans (see Useful Addresses)
- relatives of clients.

It is advisable that the Group should be responsible for ensuring that all new staff are trained in bereavement management by providing them with the necessary information and support.

## **9 Preparation and training of staff for the management of bereavement of people with autism**

### **9.1 Loss and death**

So that the objectives listed for the proposed bereavement support groups can be achieved, it is strongly recommended that *When Dad Died* (Hollins and Sireling, 1991) be used as a basis for training staff in the management of loss and bereavement.

This is a valuable resource, for working with people who have learning disabilities. It can be used by a group with a leader who need not be an experienced counsellor or educator, but who can be confident when talking about loss and bereavement and who is willing to work through each section before presenting it for discussion. A copy of *Good Grief* (2) should be available for training and reference at all times. This is a manual for loss and death education aimed primarily at young people. (For details of both of these resources, see References.)

It is advisable to obtain a publications list from CRUSE, the bereavement care organisation, and to build up a library of helpful books and pamphlets. The local branch of CRUSE might be willing to provide a lecturer or discussion group leader. (See Useful Addresses.)

When a death affecting an establishment for adults with autism occurs, staff will, inevitably, be under pressure to make decisions, to take action and to offer comfort. Furthermore, they may be suffering personal distress because of the bereavement. Appropriate training will enable staff to react with competence and sensitivity when they find themselves suddenly confronted with all the problems which accompany a death. It is important that there should always be staff available who have received bereavement training. It is also important to bear in mind the need to review this training periodically.

## **9.2 Autism**

It should go without saying that as part of the training for the management of loss and bereavement, staff need to have a profound understanding of the handicap of autism as a basis for interpreting the grief process of those in their care and in order to know when and how to offer support and comfort.

Training courses and literature on the handicap are available from the NAS Headquarters Office and should be made available to staff. There is, however, no substitute for 'hands on' experience. 'No-one really knows about autism until they have lived with it for at least two years' (Brown, in *Autism*, ed Ellis, 1990).

## **9.3 Knowledge of individual clients**

### **9.3.1 Personalities**

It is impossible to offer effective support for a bereaved person with autism without an understanding of their individual personality. This knowledge of personality can be obtained only over a period of time by caring for them and observing them carefully, by having a continuing dialogue with parents and by consultation with previous carers. Staff should also familiarise themselves with the client's life story and past experiences (see Parent and Professional Partnership, 1990).

### **9.3.2 Previous losses**

Because previous losses can affect subsequent bereavements, it is important for staff to learn as much as possible of previous losses and bereavements of those in their

care, when they happened, how these were handled by carers and how the individual reacted.

The types of losses likely to have been experienced by adults with autism are:

- moving family home
- changing staff
- changes among peer group
- break-up of parents' marriage
- death of grandparent(s)
- leaving home for residential accommodation
- death of parent(s)
- siblings moving from family home
- change from school to community or hostel, or change from one type of residential accommodation or workplace to another
- loss of pet
- illness or broken limbs
- loss of precious objects (e.g. 'security blanket', favourite toy or item of clothing).

### **9.3.3 Significant facts**

It is also important to have specific information easily accessible on the client's personal file, useful not only for other purposes, but necessary at the time of a bereavement. This information should include:

- cultural or religious beliefs and traditions of the client's family
- names, addresses and telephone numbers of interested family members and other
- important people in the client's life (e.g. family friends, citizen advocate or 'befriender')
- names, addresses and telephone numbers of the client's social worker, doctor and
- other involved professionals.

Possession of these facts can be helpful when the staff need to take practical measures following the death of a client or of a client's family member such as funeral arrangements and/or informing people who need to know of the death.

The pre-counselling bereavement questionnaire provided in *When Dad Died* is a useful *pro forma* much of which can be completed before bereavement occurs. Its only shortcoming is a failure to allow space for a significant friend or citizen advocate (if any).

### **9.3.4 Forms of address**

It is essential for the effective management of bereavement that staff have accessible to them not only the names, addresses and relationships of interested family members, but also a note of how they are addressed by the person with autism. It is no good consoling an individual for the death of 'Dad' if he was known as 'Father', of 'Nan' if

she was known as 'Granny', of 'Mum' if she was known as 'Mummy' or of 'Catherine' if she was known as 'Kate'.

### **9.3.5 Religious and cultural backgrounds**

An understanding of the religious and cultural tradition of clients is essential for staff involved in the management of bereavement. This will help them to perform with competence and sensitivity the tasks listed below which they may be called upon to undertake:

- supporting a bereaved client in their grieving process by drawing on concepts
- deriving from the client's own upbringing and acceptable to their family
- accompanying a client to a funeral and/or other rituals surrounding bereavement
- preparing a client for what to expect if they participate in a funeral and/or other rituals surrounding a bereavement
- initiating funeral, burial or cremation arrangements or arranging a memorial service.

Staff may therefore need to seek information on religious and cultural customs and rituals from family members of clients and also from local ministers of religion, rabbis or leaders of other religious groups. They are likely to discover that such people are pleased to be able to help.

Information on humanist and non-religious funerals and cremations can be obtained from the British Humanist Association or the National Secular Society (see Useful Addresses).

*When Dad Died* includes a section on Religions and Culture and gives suggestions for further reading. Also useful is the book edited by Alan Brown, *Religions, A Study Course for GCSE* (see References).

### **9.4 Practical arrangements**

If the death is that of a client, staff may find that they need to be responsible for the practical arrangements for notification and registration of the death, the funeral, cremation or burial. If a doctor deems it necessary to report the death to the coroner, there may be a post mortem examination of the body and possibly an inquest. So that staff may prepare themselves for what to expect, and for the responsibilities they may need to undertake, they should read and keep on hand for reference *What to do When Someone Dies* and *What to do After a Death* (see in particular the chapters on *How a Death is Registered* and *Paying for the Funeral*). The former is available from the Consumers' Association and the latter is obtainable free of charge from the DSS (see References). Information booklets may be available from local undertakers and from the local cemetery and crematorium.

It may be wise for staff to get in touch with several local undertakers so that they may brief themselves on what is involved in arranging a funeral and the options which are available. They should be aware that undertaking is a business and that efforts are made to sell as many services as possible. When arranging a funeral, it is important to

obtain at least two estimates and compare costs. In fact, there can be a great deal of flexibility in funeral arrangements, and it is possible to organise a simple, dignified and relatively inexpensive funeral in which the mourners can take an active part. CRUSE advise that a good training strategy would be for staff to visit an undertaker (making clear that it is a training exercise) and negotiate the type of funeral that they would like to have for themselves. They also suggest that those responsible for funeral negotiations be prepared to arrange for someone not directly involved to accompany them to give an objective view and to support them in asking for time to think about and discuss options before making decisions.

Staff may also find it helpful to attend an open day at a crematorium so that they will know what to expect if they have to arrange a cremation.

### **9.5 Getting to know the local vicar**

If it is possible to establish a link with a sympathetic local vicar, this can be invaluable when the time comes for supporting bereaved clients or staff, or making arrangements for a funeral, burial, cremation or memorial service. A number of establishments have already made these links by enabling their clients to attend Sunday services or services at Christmas and Easter. It may be wise to associate the vicar with staff training in the management of bereavement.

## **10 Preparation of people with autism for loss and bereavement**

### **10.1 Need for preparation** (see References for publications mentioned)

An individual's ability to deal with any crisis depends in great measure upon their preparation for it. It is now generally agreed that loss and death education for children, when developmentally appropriate, helps to reduce fears and anxieties about death and dying (*Good Grief (2)*). The *Good Grief* manuals have been compiled for the purpose of educating children for loss and death so that these experiences can be understood as a natural part of life. They help children to be aware of their own and others' needs at times of loss and also to understand the grieving process. *When Dad Died* has similar objectives for the learning disabled. As mentioned previously, all these are also invaluable resources for staff training.

The same arguments for death and loss education for children and for the learning disabled apply to people with autism. As part of their right to share in normal experiences and to be taught how to manage their own feelings, they should be given opportunities to prepare for loss and death so that they are enabled to deal with them when the time comes to do so. Their emotional immaturity and their high level of anxiety, as well as difficulties in transferring ideas from one setting to another, confirm the need for this preparation to be undertaken with caution and a profound understanding of the individuals concerned. The supportive environment provided by services for people with autism should ensure that it can be carried out in a controlled and positive way.

### **10.2 Training for saying goodbye: endings and new beginnings**

Staff will wish to bear in mind the importance of preparing people with autism for the losses which can occur in everyday life so that having handled these 'little deaths', they may become more able to cope with major bereavements. They will need to be made aware of saying goodbye to things and people in their lives, and of turning in a positive way to new beginnings. Some clients find it difficult to part from their families at the end of home visits and they should be helped to overcome their distress by being encouraged to look forward to pleasurable activities on their return to their care unit as well as to think about future home visits.

Another common loss in services for people with autism is departure of staff. This can provide opportunities for rituals of farewell such as parties and gifts. It is argued that because of the effects on clients, staff should be careful not to let ties become too strong, but if the ties are that of friendship with no pathological overtones, it is depriving clients of real life experience to discourage them.

Opportunities can be provided for keeping up contact with staff who have left by telephone calls, letters and visits and it can be pointed out to clients how these actions help to convert loss into gain.

### **10.3 Memory books**

Those clients who are capable of doing so and for whom it is appropriate might be encouraged to compile 'Memory Books' (see Parent and Professional Partnership - Section 14.2 on Life Story Books). These could include pictures of happy incidents in their lives, family holidays, letters and postcards from home, and photographs of family members and pets at different stages of their lives. Aside from giving pleasure during moments of relaxation, these books, with assistance from staff, may help clients to understand the concepts of the flow of life and of ageing. They may also help, in due course, with the grieving process and with learning that reminiscences about family members or pets who have died can be a rewarding pastime.

As part of this exercise, videos of family activities might be helpful, but these should be used with caution, as they may confuse the clients about the finality of death, if people appear in them who have subsequently died.

### **10.4 Explanations of death**

Opportunities should be taken to explain death simply and factually, as part of the life cycle, without speculation or prediction, using examples occurring in daily life, such as dead plants, dead insects and dead animals, establishing that they are biologically dead. It is likely that many people with autism will share the difficulty children with normal intelligence under the age of 10 have in grasping all three of the aspects of death, - that it is inevitable, irreversible, and universal (Hollins and Sireling, 1991). However, children who have been prepared with a good biological explanation of death, may be more able to accept and understand the concept of an after-life (Schaeffer and Lyons, 1988).

Staff themselves may be uncertain whether the death of a person is the final end or whether there is such a thing as immortality, but, as advised in *Good Grief* (2) to say

that 'No-one yet knows' but that people are still trying to find out is preferable to saying 'I don't know'.

All of the world religions believe in the continuation of the soul after death: Hindus, Buddhists and Sikhs believing in reincarnation (that the soul returns as a new person many times); Christians, Jews and Moslems believing that a person lives only once, and that after death their soul will go to heaven or hell.

*Good Grief (2)* includes a very good section on *Grief in Children* in which beliefs about death are simply explained. This can be summarised as follows:

There are two aspects of death, the body and the spiritual aspect.

### **1 The body**

What happens to the body can be understood by children if it is explained simply - that the dead person cannot have feelings, cannot feel hot or cold, hurt or sick. His dead body is of no use to him. A simple explanation is then given of cremation and burial.

### **2 The spiritual aspect**

This is divided into three viewpoints:

i There is no continuance of the individual spirit

ii There is a continuation in some form. People die when they have done the work they have to do, but life may continue in a different way. Some children have found the concept of the life cycle of insects helpful (see *Waterbugs and Dragonflies* by Doris Stickney) or even the concept of the persistence of atoms and electrons after the cremation of the body

iii Children should be told that there are differing points of view on the religious aspect of the soul and spirit. Abstract religious ideas are not necessarily helpful and Christian concepts are particularly difficult to understand. Children find it easier to come to terms with pantheism and reincarnation.

The chapter goes on to discuss three aspects of death which particularly concern children:

**1 Are dead people sleeping?** A clear distinction should be made between sleep and death. Sleep gives rest and renewal. Death is when the body stops working.

**2 What happens to dead people?** Our bodies wear out. Our spirit or soul, which enables us to give and receive love never wears out. We cannot see it, but people of all religions believe it lives on after we die. (The analogy is offered of a person leaving a house, which then ceases to be a home.)

**3 What is heaven like?** The spirit or soul no longer experiences the sadness and troubles we have on earth. It goes to heaven which is where God is. Because God is

love, heaven is a place full of love. No-one knows what heaven looks like or where it is.

It may be that these concepts are too difficult for most people with autism to understand. As with children, the most effective explanations are those which are simple and which draw as far as possible on the individual's own experiences. It must be borne in mind, however, that introducing discussion which will cause anxiety in a person with autism will be counterproductive. It should also be emphasized that in discussing concepts of death, staff must be careful not to confuse clients with ideas which might conflict with their cultural backgrounds.

### **10.5 Anxiety and misconceptions about death**

Children without learning disabilities may become fearful and anxious about death and there is evidence that people with autism can also suffer in this way. This anxiety may arise in different ways. They may be unconcerned about deaths of older people like grandparents, but anxious when they hear of deaths in their own age group. If they have lost one member of the immediate family, especially a parent, they may be fearful of losing the remaining family members. They may feel threatened by deaths represented on television. Staff may find that they need to reassure those in their care, playing down the likelihood of imminent death of the client or of family members or, if appropriate, drawing on the concepts of the continuation of life in some form. There is a particular need for staff to be vigilant in regard to the more able people with autism, who may become obsessed with the idea of death and of taking their own lives.

Both children and people with autism can have bizarre and distorted ideas of death. If staff detect misunderstandings about death in a client, they should try to clarify their source and nature by sensitive questioning and observation, in order to tackle them effectively. An example of how this type of misunderstanding can arise is that of a young school leaver who was convinced that his own death was imminent. He knew that a staff member had died and therefore had left the premises, and he had watched older pupils depart, never to be seen again. When the staff discovered the source of his anxiety, they were able to arrange for him to speak to those pupils who had left, who told him about their lives in a new setting.

### **11 Helping parents to prepare for the future welfare of their family member with autism after their own deaths**

If communication between staff and parents is well established, staff will be in a position to encourage parents to prepare for the future welfare of their family member with autism after their own deaths. This preparation has five components:

- 1 Drawing attention to the need to prepare for emergencies and sudden death
- 2 Arrangements for a 'successor parent' and/or citizen advocate
- 3 Restructuring of the relationship between the parent and the family member with autism

4 Taking measures which will help to comfort the client when bereavement occurs

5 Wills, trusts and visiting schemes

6 Parents' own funeral and burial or cremation arrangements.

Staff will wish to make every effort to offer practical advice and support regarding the first four and to encourage parents to seek specialised advice regarding the last two.

### **11.1 Preparation for emergencies and sudden death**

Staff should advise parents who live alone and who have their family member with autism on home visits that they should make an arrangement either with the staff caring for the client or with a reliable friend or relative to telephone them at an agreed time every day, or, alternatively, to undertake that they themselves will telephone at an agreed time. If contact is not made, the staff, relative or friend can immediately take whatever action is necessary.

### **11.2 Arrangements for the appointment of a 'successor parent'** (see Parent and Professional Partnership, Section 14.3)

If parents are convinced of the need to appoint a 'successor parent', it is helpful for all concerned - client, parents and staff - if they have been selected while the parents are able to take an active part in briefing them for their role. The 'successor parent', who ideally should be closer in age to the client than to the parents, is usually either a sibling of the client, a relative or a family friend, but they should have expressed a clear wish to serve in this capacity. Staff will need to be informed of who will be taking on this role so that they can co-operate with the parents in fostering and maintaining the relationship between the 'successor parent' and the client in any of the following ways which seem appropriate:

- encouraging the 'successor parent' to visit the client
- encouraging them to have the client for home visits so as to avoid the termination
- of home visits on the death of a parent
- including them in discussion of the client's progress and future development
- including their names on mailing lists for the in-house news magazine and announcements of activities and developments affecting the client

Whether or not siblings have been chosen as 'successor parents', staff will wish to build up a relationship between them and the service caring for the family member with autism, but this needs to be undertaken with sensitivity as some siblings may not wish to become involved.

### **11.3 Arrangements for the appointment of a citizen advocate** (see Self-Advocacy (1992), Section 2.6)

Parents have normally served as advocates on behalf of their family member with autism and it is assumed that the 'successor parent' will take over this role. However,

staff may consider it wise to reinforce their clients' access to effective advocacy by appointing citizen advocates for them, preferably in co-operation with the parents.

A citizen advocate is an individual (usually non-disabled) who serves as an advocate for the client, representing the interests of the client as if they were their own. So that there may be no conflict of interest, a citizen advocate should be independent of any service directly affecting the client and they should have no familial connections.

The document on Self-Advocacy (Section 2.6.2) offers suggestions on how citizen advocates can be identified. Staff, with the consent of parents, may need to take an active part in the selection and appointment of citizen advocates because they may be more likely to have access to groups able to provide them. As soon as a citizen advocate is appointed, they will have a standing in relation to the client which must be recognised by the service caring for them.

A conscientious citizen advocate will wish to get to know their partner well so that they can represent them effectively and staff will wish to promote this by the following means:

- encouraging discussion of the client's personality and interests whether by telephone or in person with those who know them
- keeping the citizen advocate informed of the client's activities
- welcoming visits to the client by the citizen advocate
- ensuring that the citizen advocate is invited to all case conferences affecting the client.

#### **11.4 Restructuring the relationship between the parent and the family member with autism**

By reason of their resistance to change, and distress if changes are made, people with autism may compel parents to observe a rigid routine of home visits, family holidays and visits to the establishment caring for them. They may also impose other demands such as gifts of particular food or objects or the maintenance of certain behaviour by parents. As parents age, they are less able to meet these demands and anxiety results, both on the part of the person with autism and the parents. The cessation of home visits by the client at Christmas, Easter and birthdays can be particularly traumatic both for the client and their parents.

Staff support is essential if parents are to be enabled to unlock themselves from these demands in a controlled way so as to cause themselves and the client the minimum of distress. Parents should be advised and enabled gradually to reduce the length and number of home visits and holidays, substituting visits to the establishment, and introducing flexibility into the timing both of home visits for the client and visits to the establishment by the parents. If appropriate for the client, staff could provide support by including parents in meal times at the establishment, and in outings in which the family member with autism is a participant. Staff can also help by arranging local overnight accommodation for parents living at some distance from the establishment; a number of establishments help by providing guest rooms for parents. Staff support is also needed if parents are to unburden themselves of other demands

made upon them by the technique of gradually reducing the response to these demands until they eventually disappear.

### **11.5 Taking measures which will help to comfort the client when bereavement occurs**

It can be comforting to a bereaved person to be given items of furniture or particular objects associated with the deceased.

A person with autism may be attached to objects in their bedroom in the family home which they might like to have in their bedroom in the residential setting when visits to the family home are no longer possible.

If, without causing distress to the family, the staff can find out about such items in advance, they can be used as sources of comfort to the client when the time comes to do so. Parents might be encouraged to include a letter with their wills specifying items to be given to the client. Although it is known that some people with autism have derived comfort from being given things which previously belonged to a deceased person who was close to them, others may react negatively to objects being out of the context with which they were associated, including their own possessions which they associated with the family home.

If they consider that the proposal might be welcome to them, staff might wish to suggest to individual parents that they write a letter to their family member with autism which can be given to them after the parent's death, expressing their love for them and recalling particular happy experiences that they shared. It is important that such letters be **dated** so that the client is not given the impression that the parent has returned from death. This device might be suitable only for some, but parents should be given the option of writing such a letter, to be kept by the staff on file and to be given to the client when the staff consider that it might be a source of comfort.

The proposed Bereavement Support Groups (see Section 8 above) might wish to devise some means of recording measures taken as suggested in this section, so that appropriate action can be taken when bereavement occurs.

### **11.6 Wills and Trusts** (see Parent and Professional Partnership, Section 13 and *After I'm Gone*, by Gerald Sanctuary (1991) - see References)

If their relationship with the parents enables them to do so, staff may wish to encourage parents who have not already prepared their wills with appropriate professional advice, to consult the MENCAP Legal Department or a solicitor thoroughly familiar with all the financial and legal problems relating to people with learning difficulties so that their wills may include provisions in the best interests of their family member with autism (e.g. Deed of Settlement with the National Trustees for the Mentally Handicapped). It might also be suggested that parents consider joining the MENCAP Visitors' Scheme. It is essential that parents inform those caring for their family member of what action they have taken so that if, after their deaths, staff wish to call upon funds to provide something special for a client such as a piece of equipment or a holiday, they are enabled to do so.

Staff may wish to suggest to parents that they include a section in their wills specifying that their trustees ensure that resources from their estate be available to enable their family member with autism on their death to be accorded a funeral and burial or cremation and memorial of the same quality as that expected by any other member of their family. If parents decide to make this provision, staff should be informed.

### **11.7 Parents' own funeral and burial or cremation arrangements**

Again, if their relationship with the parents enables them to do so, staff may wish to advise them, if they are proposing their own funeral and burial or cremation arrangements, to consider making suggestions for how these rituals might be made meaningful for their family member with autism and how they might be enabled to participate in them. Parents may wish to discuss with staff how these objectives might be achieved and they should, in any case, inform staff of their wishes in this regard, perhaps by means of a letter to be included with their wills, a copy of which could be attached to the client's file.

Staff may need to remind parents, particularly those who wish their remains to be cremated, that some people with autism need a focus for their grieving process in the form of a memorial stone which they can visit and where they can plant a rose bush or lay flowers. It may be appropriate for parents to suggest that the family member with autism be enabled to help in buying the memorial stone.

## **12 Anticipated death**

### **12.1 Whether to inform the client**

Although it is not conclusive, there is some evidence that if death is anticipated, the grieving process is less difficult for the bereaved than in the case of sudden death (Worden, 1988). Anticipated death can lead to pre-death bereavement, and it can also be a source of acute anxiety (Worden, 1988). Staff will therefore wish to consider carefully, in the light of their knowledge of the client's personality, whether or not they should be informed of the impending death, and if at all possible, to discuss the matter with the family before making a decision. One young man with autism who knew that his father had a weak heart was able to accept and understand the fact of his death when he was told that his father died of a heart attack, although he suffered acute grief reactions.

### **12.2 Visiting the dying**

If a client is given the opportunity to visit their dying relative in hospital and to say goodbye, it may help them to accept the finality of death and be a positive factor in the grieving process. (See *When Dad Died* in which the son visits his dying father.) Staff will wish to discuss with the family whether it is in the client's interest to visit, bearing in mind that some might find the occasion unduly stressful or a source of anxiety. It may be unwise to plan a visit if the patient is on drips or some sort of life support. If it is agreed that the client should visit, careful preparation should be made such as:

- ensuring that the staff member escorting the client is confident of carrying out the difficult task of visiting someone who is terminally ill
- briefing the client so that they will know what to expect.

Staff should remember that the visit need not be a long one, and that conversation is not necessary. The client can sit beside the patient, perhaps taking their hand.

### **12.3 Initiating bereavement management**

Staff will wish to take advantage of the time allowed by an anticipated death by giving consideration to the measures relating to bereavement management described in the following sections.

## **13 Management of bereavement affecting an individual client**

### **13.1 Who should tell the client of the death?**

The decision on who should inform the client of the death should be thought through carefully. If the death is that of a family member or someone close to the family, the decision on whether the client should be informed by a member of staff or a family member should be reached in consultation with the family. There are examples of parents who were unwilling to tell the person with autism of the death of someone close in order to avoid the devastating impact on them, but withholding this information cannot be considered good practice, however commendable the motivation.

It is important to bear in mind the fact that the informant may become the target of aggression by the client when they express the anger characteristic of bereavement, so it may be unwise, for example, to permit a mother living on her own to undertake this task. For the same reason, if it is agreed that a staff member should be the informant, the same person might not be the appropriate person to undertake the support of the client through the grieving process. The informant should be supported by another staff member and a quiet location should be chosen, where there will be no interruptions.

### **13.2 How to inform the client**

Staudacher (1988) gives some practical advice on how to inform a child about death, which can be adapted to people with autism, as follows:

- use language appropriate to the understanding of the client
- tell the truth, without giving unnecessary or disturbing details
- do not expect the client to respond in a way 'acceptable' to staff, i.e. with overt sadness
- observe how they appear to be feeling
- allow the client to release their feelings
- allow the client to take the lead and ask questions (in some circumstances they may need sensitive prompting)

- answer all questions readily and honestly; if there is no answer, say 'No-one knows'; if an answer is not immediately available, undertake to obtain it as soon as possible
- reassure the client that their life's routine in the establishment will go on and that they will continue to be cared for (bearing in mind that home visits may have to cease)
- show affection and support.

### **13.3 Terms in which the death should be explained**

A simple, factual description of death is recommended both for children and for those with learning disabilities (Schaeffer and Lyons, 1988 and Hollins and Sireling, 1991) along the lines of:

'His/her body won't work any more. It can't move, talk, walk, see or hear. He/she is not asleep, has stopped breathing, can't eat, drink, feel hot or cold.'

There should be no suggestion that there is hope of return (but see mention in Section 10.4 of reincarnation and paragraph below) and euphemisms such as 'gone to sleep', 'left us', or 'you have lost your father/mother' should be avoided as they lead to confusion and distress. In some cases, it may be helpful to use the techniques of asking the client to repeat what they have been told. Any misapprehensions about death, its nature and cause, should be detected and cleared up immediately.

The ability of the client to understand what they are told about the death may affect their ability to work through the normal grieving process (McLaughlin, 1986). Staff can help by doing everything in their power to give clients an understanding of the death at a level at which it can be absorbed. Viewing the body can be the most effective means of accomplishing this. One young woman, without speech, who was taken to view her mother's body after death, appeared to understand immediately the irreversibility of death because, having been unable to wake her mother, she signed, 'Empty, all gone'. Maureen Oswin in her book, *Am I Allowed to Cry?* describes how a young woman without speech was helped to learn about her mother's death. (See References.)

The terms in which death is explained to the client should be discussed with the family and every effort should be made to comply with their wishes. This advice may run counter to the recommendation of a purely factual explanation of death, but if the family wish the client to be told that the deceased 'has gone to heaven' or 'is with Jesus', this wish should be respected, although it should be pointed out that confusion may arise if the client should view the body or attend the funeral, cremation or burial. There are examples, however, of successful resolution of grief by people with autism who have been told that the deceased has gone to heaven, yet who have participated in the bereavement rituals. Some clients have seemed to accept 'gone to heaven' as a factual explanation of someone having gone to a specific place where they themselves cannot at present go. Others have found comfort in the concept of reincarnation.

If the client has experienced a previous bereavement, it is important to explain any subsequent death in the same terms. Again, the family may need to be consulted.

### 13.4 Explaining the cause of death

Deaths have been categorised under four headings: natural, accidental, suicidal and homicidal (NASH) and the type of death can have an effect on the grieving process (Worden, 1988). The first two types of death are more easily explained to a person with autism. Information available at present indicates that people with autism sometimes ask 'where' or 'when' a person died, but they seldom ask 'how', although staff should be prepared for them to do so. Those who do ask 'how' may be better able to assimilate the answer.

In explaining the death, it is important always to be **honest** and **consistent**, without giving details which are unnecessary or disturbing (Staudacher, 1988). The cause of **natural death** can be explained by saying that the deceased 'was very old so that his (or her) body wore out and stopped working' (Schaeffer and Lyons, 1988) or that they were 'fatally' (or 'terminally') ill, 'and the doctor could not make them better'. Care should be taken, when mentioning illness, to avoid using the expression 'very ill' which might later be used on an occasion when the client is ill, leading them to believe that they are on the point of death.

An **accidental death** can be explained by saying that 'his/her body was so badly hurt that the doctor could not make it better, so it stopped working' (Schaeffer and Lyons, 1988).

Advice concerning the impact on children of bereavement by **suicide** emphasizes that they should be told the truth simply and honestly because experience has shown that they are likely to find out indirectly or to realise that they are not being told the truth, in either case, with severe adverse consequences to themselves. If there is no doubt that the deceased planned to kill themselves, the death should be explained to a child along the following lines: 'Sometimes a person's mind doesn't work right. They can't see things clearly and they felt the only way to solve their problems was by ending their life' (Schaeffer and Lyons, 1988). This would not be an appropriate explanation to offer a person with autism. The more able person with autism is more likely than the majority to ask how the death occurred and might even ask if it was done on purpose. On the other hand, there are dangers in informing them of the suicide, because there is a high level of severe depression in this group, sometimes leading to suicide. It is strongly recommended that if a person with autism should be told that their family member has committed suicide, specialised counselling help should be sought, which should be available throughout the bereavement period.

If the bereaved client is in residential care, has a very limited capacity for understanding, and is highly unlikely to find out about, be informed of, or even comprehend the notion of suicide, it is recommended that the cause of death not be mentioned.

Should it be necessary to speak of the mode of death, the explanation should be confined to the minimum of necessary information such as 'they took too many pills, which made them fatally ill and the doctors couldn't make them better' (overdose), 'a train ran over them and their body was so hurt and broken that it can't work any more' (threw themselves under a train), or 'their body was so hurt and broken, it can't work any more' (hanging).

It cannot be overemphasized that if a client loses someone close to them by suicide, staff should assess the whole situation carefully. They must be particularly sensitive and discreet if the client is at the able end of the autistic continuum.

Much of the same advice applying to suicide applies to **homicide**. Specialist counselling help should be sought if at all possible.

### **13.5 Deciding on whom to inform of the bereavement**

If possible, staff should discuss with the surviving members of the client's family who should take responsibility for informing those, other than family members, who should be told of the bereavement, such as the client's advocate or 'befriender', their doctor and social worker, whose names, addresses and telephone numbers should already be easily accessible on the client's file (see Section 9.3.3 above).

**All** staff members, both those in the residential setting and the workplace, who are likely to come in contact with the bereaved client should be informed quickly and privately. So that absolute consistency can be maintained in the management of the bereavement, staff should be told of any significant facts relating to it such as:

- relationship of the client to the deceased, both familial and emotional (whether close, whether contact was frequent and regular, etc.)
- if the death was anticipated, whether the client was aware of this
- the terms in which the death was explained to the client, and how the client reacted
- whether the client will participate in rituals surrounding the bereavement
- previous losses suffered by the client.

### **13.6 Deciding who should support the client**

One of the functions of a Bereavement Support Group is 'to ensure that clients are supported during their grieving by designated members of staff who understand the grieving process'. Decisions regarding those who should undertake this role in regard to individual clients should be preceded by consultations with those who know them best, including family members if possible. If a death is anticipated, advantage should be taken of the extra time to select suitable staff for this role and to remind them of the problems which may be involved.

The relationship to the client and the ability to feel comfortable when talking about death, are the most important factors in the selection of a member of staff to support a bereaved client.

Ideally, the key worker, assisted by another staff member who knows the client well, would serve in this capacity, but there may be good reasons why certain individuals might not wish to undertake this role, such as lack of experience of bereavement or concern that a bereavement experience of their own might be brought to the surface again. No-one who has suffered a recent bereavement should be called upon to act as bereavement support for a client. A bereavement support worker need not necessarily be a member of the care staff. They might be a member of the maintenance or office staff with whom the client has a particular affinity.

The bereavement support worker should be prepared:

- to keep all staff who come into contact with the client informed of their reactions to the bereavement and of their special needs deriving from it
- preferably with the agreement of the client's family, to enable the client to participate in the rituals surrounding death
- to comfort the bereaved and facilitate the grieving process.

It is recognised that because of staff rotas, it is not possible for the support worker, or even the person who assists them, to be on duty at all times during the bereavement process, which may last more than two years, but staff caring for the bereaved client must have **access at all times** to a member of staff (preferably a member of the Bereavement Support Group) who can provide them with support and guidance.

### **13.7 Participation in rituals surrounding death**

It is recognised that participation in the rituals surrounding death is helpful in the grieving process for those without learning disabilities. They provide an opportunity to face the reality of the death, to begin to come to terms with it, to say farewell to the deceased, and to share grief with others. It is now accepted that most people with learning disabilities should be offered the opportunity to participate in bereavement rituals, and this is no less true for people with autism. Accordingly, provided the bereaved client has not expressed a clear wish not to participate in these rituals, staff should be prepared to enable them to view the body of the deceased, to attend the funeral and to attend the burial or cremation. They should **not** be excluded because it is thought they would not understand or might be upset. Staff should give clear advice to the family of the client along these lines, and they should always ensure that one or two staff members who know the client well will accompany the client on these occasions, so that the family members, who may be seriously distressed by their own grief need not be responsible for them. On the other hand, there may be good reasons why the client should not participate in some of the rituals (e.g. viewing the body, attending the funeral) or there may be strong family objections to their doing so, and these views must be considered.

If a client is to participate in any of the rituals surrounding death, it is essential that staff make it quite clear what they should expect. It may therefore be helpful, if at all possible, for staff to gain as much information as possible, either from family members, the priest, or religious leader and also, if time allows, by visiting, or better still, taking the client to visit, the relevant locations in advance - the church, synagogue, temple, and cemetery or crematorium.

Specific information which might be helpful for the client to know might include the actions of the mourners at the funeral (singing hymns, saying prayers for the deceased, the fact that the priest or religious leader may speak about the deceased), the meanings of the rituals (as much as can be understood by the client), and the fact that the body will be moved in the coffin to the front of the church. The client should also be told that it is all right to cry at a funeral.

#### **13.7.1 Viewing the body**

It is known that this can help the bereaved to understand the finality of death (Section 13.3 and *When Dad Died*, 1991). If it is agreed that the client should view the body, care should be taken to ensure that they are made aware that the **whole** body is there. It is known that children, for example, seeing only the head of the deceased in the coffin, have concluded that it has been severed from the body (Schaeffer and Lyon, 1988). This is a misapprehension to which a person with autism might also be liable. In some instances it could be helpful for the client to touch the body. On the other hand, viewing the body should be avoided if it is likely to cause distress to the client, either because of the client's expressed choice or what is known of their temperament, or because the body has been mutilated in some way.

### **13.7.2 Funeral**

If possible, staff should agree with the family beforehand where they and the client should sit in the church, synagogue or temple. It may be wise for them to sit in the back, so that they can make an inconspicuous exit if the client is in distress. The coffin and the fact that it is holding the body should be pointed out to the client. If flowers are an acceptable part of the culture, it would be wise to have encouraged the client to buy and bring flowers to place on the coffin and they should be allowed to touch it.

### **13.7.3 Burial**

If the body is to be buried, it should be made clear to the client that it will be protected from mud and rain by the coffin. The client may wish to join the other mourners in throwing a handful of earth on the coffin.

### **13.7.4 Cremation**

If the body is to be cremated, the process of cremation should be explained to the client and they should be reassured that the deceased will not feel pain as they are no longer able to feel anything.

### **13.7.5 Visit to the gravesite or memorial stone**

Even if, for various reasons, the client has not participated in the other rituals, staff should try to enable them to visit the gravesite, or the memorial stone, as this can be a helpful way for the client to say farewell to the deceased. The significance of the grave or the memorial stone should be explained to the client in terms they can understand, and they should be enabled to make some gesture, such as buying and placing flowers by the stone, or planting a tree or rose bush. It may be appropriate to arrange further visits, particularly if the client requests it. Visits to the gravesite or memorial stone may help the client to come to terms with their bereavement and consideration should be given to whether they should be enabled to visit it on the occasion of the anniversary of the death, or on other anniversaries, as a way of remembering the deceased. It is desirable to keep the surviving family members informed of these visits, but their permission is not essential.

### **13.7.6 Memorial service**

Some families, particularly if the deceased has been of some prominence in the community, organise a memorial service, usually some weeks after the burial. It may not be appropriate for the bereaved client to attend the service because of the large number of people present, but if the family expresses a wish for the client to attend, or if the client wishes to do so, staff should be prepared to explain the significance of the service and to accompany the client.

(In the section on 'Remembering' in her book *Am I Allowed to Cry?*, Maureen Oswin lists a number of helpful suggestions of how people with learning difficulties can be associated with the activities which follow bereavement, such as being told what is happening to the family home and helping to sort out the belongings of the deceased. See References.)

## **14 Comforting the bereaved client and coping with grief reactions**

**(see Appendix II for reactions of people with autism)**

In comforting the client, staff must be careful to ensure that the **timing and duration** of the grieving process and the 'tasks of mourning' are determined by the client. The role of staff is to facilitate the grieving process by such measures as:

- being there when needed
- anticipating reactions
- listening and reading cues
- intervening even though help is not requested
- asking how the client feels and supplying words to help them describe how they feel, being careful not to plant ideas
- talking about the deceased and experiences they shared with the client
- reassuring and comforting
- explaining the grieving process, at an appropriate level
- if the client will accept it, physical contact such as touching, holding, or massage
- ensuring that the bereaved is comfortable and not in physical pain or distress
- ensuring that the bereaved has a private place in which to grieve if they indicate that they need it.

*Good Grief* (2) lists some Do's and Don'ts under the title of *How to Help Someone Suffering from Loss*, which can be adapted to people with autism.

Staff will wish to take particular note of the common reactions to bereavement listed in Appendix I under 'As the early shock wears off', so that they may have some idea of what the client may be suffering. It is helpful to focus on some of these reactions, bearing in mind the fact that a number of them can derive from causes other than bereavement. A knowledge of the client and good powers of observation may help staff members to determine the causes of distress, but it is safe to assume that bereavement may be a powerful factor for two years or more after the death of someone close to the client.

### **14.1 Anger**

This may be directed at the one who died, for abandoning the bereaved. It may also be directed at the person who broke the news of the death, or it may be a generalised anger. Anger may also arise when activities provided by the deceased are no longer available. Staff should enable the client to express this anger without harming themselves or others, or damaging property. One young man with autism expressed his anger by breaking up the furniture in his room. Had those caring for him been better prepared, they might perhaps have been able to divert his anger into vigorous exercise, hitting cushions or a punch bag, knocking a ball about, or tearing up old telephone books.

## **14.2 Guilt**

This may arise from the 'magical thinking' characteristic of young children who have been bereaved, who think they might have caused the death by their own actions. Guilt is anger turned on oneself, but in people with autism it is often expressed as overt anger. Staff will wish to avoid suggesting to a client that they might have feelings of guilt, but if they have evidence that this is so, they should reassure the client that the death was inevitable and not caused by their own or any other individual's actions, being careful to use the same terms in which the death was originally explained.

## **14.3 Anxiety, fear, panic**

Anxiety, fear, panic are all common responses to bereavement. These feelings are likely to be heightened in people with autism, not only because of loss of someone important in their lives who may have represented stability and security, but also because of the changes which almost inevitably follow bereavement, which are likely to be very threatening to a person with autism.

The bereavement may also give rise to a fear of their own death, possibly resulting in a fear of going to sleep, or fear that other members of their family may also die (see Section 10.5).

Staff must be prepared to provide constant reassurance and to alleviate some of the effects of bereavement by encouraging the 'successor parent', a 'befriender' or other surviving members of the family to keep in close touch with the client, perhaps fulfilling some of the caring functions previously undertaken by the deceased, such as taking the client out for meals or for home visits. It is important to convince the client that they will continue to be cared for and to provide the security afforded by maintaining the usual routines of daily life. Unless the client has expressed a positive wish for change, changes in the client's life should not be introduced during the period of bereavement.

## **14.4 Depression, despair**

The client will feel acutely the emptiness and pain of loss, but **on no account** should staff try to 'jolly them out' of their grief. 'They kept wanting me to dance, but I was too sad to', was a poignant comment made by a bereaved person with learning disabilities (Oswin, 1991). Talking about the deceased, though it may temporarily exacerbate the grief, is considered necessary to recovery from bereavement (A T Carr,

1988). In order to assist this process, it is important for staff to learn something about the deceased, how they looked, their personality, the nature of their relationship with the client, and the activities they shared. It is also important to know the terms of endearment the deceased used for the bereaved. This information can not only help staff to encourage the bereaved to communicate their memories of the deceased, but it can also enable staff to speak to the client of the deceased in terms which are meaningful to them and from which they may derive comfort.

Because people with autism have difficulty in understanding and expressing their feelings, staff need to help them to do so, at a level which is appropriate for them. Staudacher (1988) gives some excellent examples of how children's feelings can be interpreted and put into words (pages 147-149). The same approach is valid for people with autism.

Staff should be vigilant to detect and to deter, if possible, thoughts of suicide, particularly on the part of the more able person with autism. Specialised counselling for the client may need to be sought. Professional help may also need to be sought for those suffering from deep and prolonged depression.

#### **14.5 Pain, appetite disturbance, breathlessness, illness**

The physical symptoms of bereavement can cause the bereaved acute discomfort. It is now generally accepted that bereavement can be responsible for the beginning or relapse of genuine illness (*When Dad Died*, 1991). One young woman with autism who lost her father suffered a serious and prolonged period of asthma combined with anorexia, necessitating being fed by hand. Of course, staff will wish to determine whether the illness has been triggered by a factor other than bereavement, such as the side effects of medication.

It is important to remember that body temperature may drop because of bereavement and it is therefore necessary to ensure that the client is kept warm and comfortable.

Good food - especially soft food (yoghurt, soup, pureed foods) - and warm drinks can be a source of comfort. Assistance with eating may also be comforting.

#### **14.6 More than usual need for sleep, sleeplessness, hyperactivity**

The bereaved may require more than the usual amount of sleep, or, alternatively, they may suffer from insomnia or hyperactivity. Staff will need to create a balance between these reactions and the maintenance of a stable routine.

#### **14.7 Nightmares**

Staff on night duty should be made aware not only of the risk of sleeplessness, but also of the fact that the bereaved may have **very** frightening nightmares. One young woman with autism dreamed she was eating meat, which turned out to be her deceased brother. If the nightmares persist, extra staff may need to be on duty, as the bereaved should be wakened, got out of bed, and given a warm milky drink, and they may need for someone to sit with them after they return to bed and while they go to sleep.

## **14.8 Regression, loss of skills**

Emotional and physical regression, increased dependency and loss of skills are common reactions to bereavement by learning disabled. They may even become incontinent or bedridden (*When Dad Died*, 1991). It is strongly advised that any form of assessment of a person with autism be avoided during a period of bereavement, as it would result in an entirely 'false reading'.

## **15 Problems encountered in bereavement of people with autism**

It is absolutely essential that those offering support to a bereaved client have not only a good general understanding of autism, but they must also know the client well and be skilled in observing and interpreting both their verbal and non-verbal reactions. The grieving process of people with autism is impeded by their disabilities of communication, and social interaction and difficulties of cognition. Staff need to be aware of some of the problems which may arise.

### **15.1 Failure to grieve after loss**

Some people with autism and others with learning disabilities do not grieve after loss (Brelstaff, 1984). These few examples do not justify an assumption that they do not have a capacity to feel emotion or that if an individual does not exhibit grief in an expected way, that they are not grieving.

Before it can be concluded that a bereaved individual is not grieving, staff need to verify their conclusion by careful observation, sensitive questioning and checking on the behaviour of the individual in other settings (Brelstaff, 1984). Furthermore, it cannot be concluded from the fact that there has not been a reaction to one bereavement that there will be no reactions to subsequent bereavements, particularly that of a second parent, which may result in the cessation of home visits and the type of caring offered by a parent.

### **15.2 Delayed reaction to loss**

Grief is often a delayed process for people with learning disabilities. They fail initially to understand the implications of their loss, but may come to feel the impact later (Kitching, 1987). One young woman with autism whose father died before Christmas accepted that she could not go home for the holiday, having been given a reason - that daddy had gone to heaven - but did not begin the grieving process until she went home the following Christmas and realised her father's absence. She then underwent a profound grieving process for a period in excess of two years.

### **15.3 Apparent failure to understand the irreversibility of death**

The failure to understand the irreversibility of death is characteristic of young children without learning disabilities (Schaeffer and Lyons, 1988). This is also true of some people with autism, although there may be an apparent failure to understand, which reflects a language difficulty rather than a difficulty of comprehension.

It is normal in the early stages of bereavement to behave as though the deceased still lives or even is present, and to experience difficulty in accepting the finality of death. It may be that the client's repeated questions about the return of the deceased after the funeral and burial or cremation are their way of coming to terms with their loss. They may feel a need to check the consistency of the replies they are given or their questions may be their way of showing that they need comfort and reassurance. One young man with autism, who attended his father's funeral and cremation, persisted for some time in asking when his father would return.

#### **15.4 Uncertain and inappropriate responses to bereavement**

There have been a number of examples of people with autism who have expressed uncertainty regarding how they should react to death: 'Should I feel sad?'; 'How sad should I feel?'; 'Shall I cry?'. Others have reacted by giggling at the funeral or at the gravesite - perhaps a reflection of this uncertainty. This is also a reaction in children. Some have appeared callous and unfeeling, which is very difficult for carers - like the girl who, on the death of her mother, immediately asked when her father planned to marry again. Some apparently callous comments can be the result of difficulties with verbal expression.

#### **15.5 Disruptive or aggressive behaviour**

Because of communication difficulties, the only way a bereaved person with autism may be able to express their grief is by disruptive or aggressive behaviour. It is difficult for staff to discover whether this arises from fear, anger or guilt or physical discomfort, all of which can accompany bereavement, or whether it arises from factors altogether unrelated to bereavement which may be as diverse as effects of medication or distress caused by the behaviour of another client. Staff will, of course, by means of sensitive questioning and observation wish to discover the cause, and take appropriate action. It is important to remember that even long after the loss has occurred, the client's behaviour can be affected by bereavement.

#### **15.6 Limited means of expressing grief**

It is generally agreed that people without learning disabilities, who are bereaved, find it helpful to talk to sympathetic family members and friends about the deceased and about their feelings. Grief counselling, proven to have a very positive effect on the grieving process, involves **listening** to the bereaved and commenting reassuringly and supportively. These therapeutic strategies are unavailable to most people with autism unless staff can enable them to discuss their thoughts and feelings by sensitive questioning and by supplying appropriate words, signs or pictures. Because of the demands it makes upon them, this kind of attention may be unwelcome to the bereaved, who may find it threatening. On the other hand, unexpressed grief may go on at an unconscious level, which may precipitate symptoms of unresolved grief, such as deep depression or neurosis.

#### **15.7 Inability to request help**

Because of their disabilities of social interaction, people with autism are unlikely to seek support when they are anxious, depressed or unhappy. Again, it is necessary for

staff to intervene sensitively. Although a minority of people with autism do not apparently grieve when they lose someone close, the majority need to experience the grieving process and require help in order to do so. There is no need for staff to fear reactivation of the grief by active intervention - at least during the first few years of bereavement. It is likely to be present and should be expressed.

### **15.8 Limited number of relationships**

The person with autism - as do others with learning disabilities - has a very limited number of close relationships. Consequently, there may be a very substantial emotional investment in these relationships, with the result that when they are terminated by departure or death the effect on the person with autism may be catastrophic. Because they have a limited network of concerned family and friends, they may find it difficult to perform one of the tasks of grieving which must be worked through if the grieving process is to be completed - to effect an emotional withdrawal from the deceased and reinvest it in other relationships (Worden, 1988).

In common with others with learning disabilities, many people with autism are highly dependent for help on professional staff who may not be able to offer long-term emotional care or support.

### **15.9 Inability to seek activities which may help in the grieving process**

People without learning disabilities have access to a number of strategies which can help to mitigate their loss. They may turn to violent exercise, pursue their hobbies, seek social contacts, travel, listen to music. People with autism may not have the self-awareness, motivation or experience to seek activities which might be helpful to them, and they often cannot have access to them without help from carers.

### **15.10 Introduction of undesirable habits or obsessions**

Staff may need to intervene if undesirable habits or obsessions are introduced by the bereaved during their grieving process as a source of comfort, as these may persist long after the period of grieving, to the detriment of the client.

### **15.11 Inability to predict future change**

People with autism are unlikely to have an expectation that the pain and suffering which they are experiencing will eventually come to an end. They therefore lack yet another possible source of comfort. Staff should make every effort to explain the grieving process to them, bearing in mind that the intensity and duration of their reactions should be determined only by the bereaved.

## **16 Anniversaries**

Staff should be reminded that bereaved clients may need special attention on the occasion of the anniversary of the death and also at times of festivities such as Christmas, Easter and birthdays which they may have shared with the deceased.

## **17 Effects of previous losses and bereavements** (see [Section 9.3.2](#))

Staff may also need to be reminded that previous losses and bereavements may interact with a subsequent bereavement. The subsequent bereavement may reactivate the pain of earlier loss, the earlier loss may be actually felt for the first time, or the previous bereavement may never have been resolved (Worden, 1988). It is therefore important for staff to have as detailed knowledge as possible of the client's previous losses.

## **18 Support of surviving family members**

After the death of someone who has been close to a client, particularly a family member, staff may find that they are in close touch with the surviving family members who are also mourning the deceased. Staff should be prepared to offer support to family members in the following ways:

- keeping them informed of the reactions of the bereaved client
- helping them to understand and come to terms with the reaction of the client, in particular
- inappropriate behaviour
- apparently callous reactions
- anger, especially if it is directed towards surviving family members.

A surviving mother, for example, may be the focus of aggression from a bereaved client, as she may be held responsible for the death by the client, especially if she informed the client of the death. No surviving family member should be deterred from visiting the client because of the possibility of being the target of aggression. Staff should be prepared to be present and to intervene to protect the visitor.

## **19 Support of staff caring for a bereaved client**

One of the functions of a Bereavement Support Group should be the support of staff caring for bereaved clients as this role can be a very demanding one, requiring concentrated attention and commitment. One cause of stress can be the difficulty of determining whether the reactions of the client are the result of their bereavement or of totally unrelated factors. The anger of the bereaved client may be directed toward the staff member supporting them. The staff member may also be distressed by witnessing the grief reactions of the bereaved client. The support group should ensure that the staff member has access to one of their members at all times, not only for specific advice, but also to provide an informed and sympathetic response when they need to talk about their own feelings.

## **20 Loss of client: loss of staff member**

The loss by death of a client or of a staff member can be particularly devastating for a service for people with autism, because this type of loss may have a direct affect on a number of staff and clients. In order to cope with losses of this kind, staff need to be prepared to undertake many of the practical arrangements involved in death, such as

the registration of the death, funeral arrangements and cremation or burial (see Section 9.4).

### **20.1 Whom to inform**

All staff should be informed of any death of a client or staff member and all those clients who are likely to be affected by the death in any way. It should be borne in mind that unusual circumstances can be detected by even some of the less able clients, which can lead to the development of misapprehensions, possibly causing them more distress than an understanding of the truth. Whether clients should be informed as a group or individually depends on the relationship of the clients to the deceased and with each other. Families of clients likely to be affected should be informed.

### **20.2 Support of clients who are likely to grieve**

It is important to identify those clients who are likely to grieve for the deceased and to appoint a bereavement support worker who can help them through the grieving process and enable them to participate in the rituals surrounding the death, as described in earlier sections of this document (see Sections 13-15).

### **20.3 Support of staff**

Individual members of staff who are suffering the effects of bereavement may wish to seek support from a member or members of the Bereavement Support Group. Staff may wish to meet in a 'sharing group' where they can express their feelings about the deceased and their own bereavement reactions without fear of interruption or criticism and receive the sympathetic support of the group. The session might be introduced and led by a member of the senior staff, a member of the clergy, or a member of CRUSE, who would explain the purpose of the session and how it would be conducted. The session should be held in quiet, comfortable surroundings, with pre-arranged times for beginning and ending, and should last not more than one hour.

### **20.4 Support of surviving family members of a deceased client**

Staff may find that they are called upon to offer support to the surviving family members of deceased clients, especially if they are parents. The disability of autism, by its very nature, isolates the individual from other people, both because of the behaviour it causes and because its complexity makes it difficult for others to understand. Family members will therefore turn to staff, as being perhaps the only people who knew and liked the client as an individual and who were sympathetic to their needs. One of the factors in the grieving process is the need to talk about the deceased. Staff are uniquely qualified to listen sympathetically to surviving family members and thereby help them to come to terms with their loss.

### **20.5 Support of survivors of suicide**

If a client has taken their own life, both staff and surviving family members may find this particularly difficult to come to terms with and may need expert counselling. The book by Alison Wertheimer, *A Special Scar*, is helpful in explaining the experience of people bereaved by suicide (see References).

## **20.6 Memorial service or ceremony**

The opportunity to say 'goodbye' expressed by some form of ritual can be a great help in the grieving process. A memorial service for the deceased staff member or client, which those who knew them - both staff and clients - can help to organise and in which they can participate, together with family members of the deceased, can provide this opportunity. It also provides a means of recalling the life of the deceased in a positive way. The local vicar or other appropriate clergy can be asked to officiate and to advise on the form the service might take. Alternatively, or in addition, it may be desirable to have a more informal ceremony such as setting up a bench, planting a tree, erecting a memorial stone. Advice on memorial stones can be obtained from CRUSE, who can provide a list of addresses.

If a group is to attend a funeral or memorial service, they should not go out in a minibus as if on an outing. Despite the expense, cars should be used as being more respectful and normal. (Oswin, 1991.)

## **21 Grief and growth**

The ultimate aims of staff should be to enable clients not only to achieve a successful resolution of grief, but also to enable them to transform their experience into a source of strength for themselves and of benefit to others. There have been some very moving examples of this achievement among people with autism who, having experienced bereavement themselves, have offered comfort to other clients - and even staff - who were undergoing a grieving process. This is a reminder of the opening quotation:

'There is no growth without pain and conflict and no loss that cannot lead to gain.'

(Lily Pincus, 1961)

Written by Helen Green Allison with the advice and support of the Principals of services for people with autism.

## **The management of bereavement in services for people with autism (Appendices, References and Useful Addresses)**

(Code of Practice Procedures, Document 3)

### **Appendix 1**

#### **The process of grieving**

There follows a brief account of the grieving process and some of the factors which determine how individuals may react to bereavement. Whether or not they have

learning disabilities, people react individually to grief, but most people experience at least some of the **common responses to bereavement**. These are summarised below:

**Initially:**

- **Shock**, numbness, disbelief, denial.
- One or more **physical symptoms** such as lack of energy, trouble concentrating, remembering, making decisions, hyperactivity, thinking about wanting to die, sense of unreality.

**As the early shock wears off** and the impact of the reality of the death is felt, people may experience the following reactions:

1 **Emotional:** Anger with the deceased or with those believed to have failed to prevent the loss, guilt, anxiety, fear, panic, depression, despair, mood swings, irritability, crying, sadness, yearning and pining, sense of being abandoned.

2 **Physical:** Symptoms such as pain, appetite disturbance, breathlessness, illness, symptoms of the deceased.

3 **Behavioural:** Low vitality, more than usual need for sleep, sleeplessness, hyperactivity.

4 **Mental:** Confusion, hallucinations, nightmares, searching for the deceased, poor concentration, regression, loss of skills, insecurity.

Resolution of grief occurs when the bereaved is able to think of the deceased without pain or anger and can recall the times they had together in a positive way.

(Caring programme, 1989; Worden, 1988.)

Many experts view grief as a process, with three identifiable stages: shock, despair and recovery. It is preferable to consider these as components which may overlap and merge into one and other, some predominating earlier in the process and others predominating later. (A T Carr, 1988).

J William Worden has identified four tasks of mourning which people must work through if the grieving process is to be completed.

1 To accept the reality of loss.

2 To experience the pain of grief.

3 To adjust to an environment in which the deceased is missing.

4 To effect an emotional withdrawal from the deceased and reinvest in other relationships.

There is no fixed time period for the completion of the mourning process and for equilibrium to be established. Normally the loss of a close relationship takes over a year and may take two years. (Worden, 1988).

**Anniversaries** are particularly difficult, the date of the death, birthdays, Christmas and other festivals which might have been shared with the deceased. (Caring programme, 1989.)

### **Determinants of Grief**

The major determinants of the **intensity and duration** of a person's reactions to grief are as follows:

- 1 **Who the deceased was**, the closeness of the relationship to the bereaved.
- 2 **The nature of the attachment**, strength, security, ambivalence of the relationship.
- 3 **Mode of death**, whether it occurred suddenly or with advance warning. It is usually easier to accept the death of a person ripe in years than that of a young person. Natural deaths are more easily accepted than accidental deaths.

Suicides and homicides are particularly difficult to accept.

4 **Historical antecedents**, the bereaved's previous experience of grieving. The irresolution of a previous bereavement may intensify the reaction to a new one. On the other hand, a successful resolution of a previous bereavement may help a person successfully resolve a subsequent one. Those with a history of depression are more likely to have difficulty in coping with bereavement than those without such a history.

5 **Personality of the bereaved**, age and sex of the person, whether they have difficulty expressing their feelings, how they handle anxiety and stress.

6 **Social variables**. Ethnic and religious background are important in determining the rituals of mourning and the form of social support available.(Worden, 1988.)

**Unresolved grief** or complicated grief occurs when the bereaved have difficulty in resolving their feelings about their losses and therefore fail to complete the 'tasks of mourning'. This may result in prolonged and excessive grief and may include masked grief reactions such as physical symptoms and maladaptive behaviour.

Note: The above account is taken from the following:

Leaflet circulated by The Caring Programme, *Coping with Grief*. The Washington Home, 3720 Upton Street, NW, Washington DC 20016, USA.

Carr, A T, 'Dying and Bereavement' Chapter 7 in Hall, John, Editor, *Psychology for Nurses and Health Visitors*. British Psychological Society and MacMillan Publications Ltd. First edition 1982. Reprinted 1988.

Worden, J William, *Grief Counselling and Grief Therapy*. Routledge, London and New York, 1983. Reprinted 1988.

## **Appendix II**

### **Grief reactions of people with autism**

Those concerned with the management of bereavement in services for people with autism have reason to be grateful to the relatives and staff who, in response to a notice in *Communication*, volunteered to complete a questionnaire on individuals with autism whom they supported during their grieving process. A particular debt of gratitude is owed to the relatives who helped with this study, as in doing so they were recycling their own experiences of bereavement.

A total of 20 respondents completed the questionnaire and the information they provided was supplemented by conversation and correspondence both with a number of them and with others. **All** of the contributions have been valuable, both in providing background for the document and in validating its recommendations. They have demonstrated how sensitive management has helped bereaved people with autism towards a successful resolution of grief. Some of the material has been used to illustrate points in the text and some is summarised in this Appendix in the form of selected case histories illustrative of a variety of grief reactions.

(The names in the summaries have been changed in order to preserve confidentiality.)

#### **ALAN**

**Age** at time of bereavement - 14.

**Described as:** highly dependent, needing constant supervision and frequent physical intervention. Able to converse, expresses preferences and feelings. Some ritualistic behaviour. High level of anxiety. Hyperactive. Mood swings. Epileptic.

**In residential school** - termly boarding at time of bereavement.

**Relationship** to deceased (grandmother): close and affectionate.

**How was bereaved told of death?** Mother told him 'Nana was very ill, so Jesus invited her to his wonderful garden. She is happy now and wants you to know she will always love you.'

**Immediate reactions.** Ran round the room with grief. Then cuddled by mother and cried on her shoulder. Said, 'Mummy, I do love you.' Then, 'Nana, oh my Nana.' Shock then set in and he did not speak for 3 days.

**Later reactions.** Epileptic attacks. Temperature, lethargy, depression. Not interested in food or drink. Stomach upset. Said he was sad and frightened. Unresponsive, 'personality change'. Concerned about mother's health. Tried to hurry past end of road where grandmother lived. Did not wish to visit her house again.

**Funerals and rituals.** Did not attend funeral. Took flowers to crematorium garden, but refused to visit ever again. Will not look towards it when he passes.

**Resolution of grief.** Happy to have his grandmother's radio, a clock, some of her pictures. Speaks of her, 'Nana liked those autumn tints' - 'Is Nana pleased with me?'

**What helped?** Warm support from mother. Assurance that Nana did not 'go away' and that he could talk about his sadness. Demonstrations of caring and affection, physical contact.

## **DEREK**

**Age** at time of bereavement - 17.

**Described as:** dependent, needing constant supervision in living and working. Speech very limited. Can express preferences and feelings. Usually cheerful but sometimes sad or worried. Occasional challenging behaviour when feeling insecure. Some periods of anxiety.

**Termly boarder at school** at time of bereavement.

**Relationship to deceased** (father): close and affectionate.

Death was anticipated but bereaved did not know of illness.

**How was bereaved told of death?** His mother told him 'Daddy is in heaven.'

**Immediate reactions.** Disbelief. Asked, 'Where is Daddy?' Was told, 'In heaven.' After that the bereaved did not comment.

**Later reactions.** No indication of awareness of loss. Asked again, 'Where is Daddy?'

**Funeral and rituals.** Did not participate in any bereavement rituals.

**Supported by:** staff at school and mother, who arranged for the bereaved to have frequent home visits and who ensured that he was aware of her affection for him.

**Resolution of grief.** Difficult to detect as no apparent grieving process.

**Subsequent bereavements.** Grandfather died 5 years later. The bereaved was told, 'Grandad in heaven', and appeared undisturbed. Never asked about him. Family dog died 9 years after father. The bereaved was told, 'Kelly is in heaven with Daddy and Grandad.' He continues to speak of him as though he were alive, 'Take Kelly for a walk.'

**Comments.** Mother is concerned about effect of her own death on her son and is pleased that her sister and elder son make a practice of arranging for him to visit them, particularly when she is on holiday.

## **DONALD**

**Age at time of bereavement** - 29.

**Described as:** dependent, needing constant supervision in living and working. Very articulate. Anxiety caused by unexpected events. Challenging behaviour only when disturbed. Normally stable. Very much concerned about world events e.g. nuclear threat, world ecology.

**Living at home and day patient at industrial therapy unit at time of bereavement.**

**Relationship to deceased** (brother): close and affectionate.

**Death was sudden.**

**How was bereaved told of death?** At the time of death he was on holiday at a Steiner community familiar to him because he had frequently spent periods of time there. As he had attended Steiner schools, he accepted their religious beliefs, including a firm belief in an after-life. Death was explained in these terms. Staff well known to him helped him through the first few weeks with excellent counselling. Was able to speak about his loss.

**Later reactions.** No particular changes in behaviour but a great need to talk about the deceased and the effect of the loss on his own life as deceased really cared about him. Read his obituaries, looked at photographs, looked at slides the deceased had sent him.

**Funeral and rituals.** Bereaved away from home and did not attend funeral.

**Anniversary of death.** For ten years was marked by rituals of reading deceased's obituaries, looking at photographs and at slides sent to him by the deceased. At the 10<sup>th</sup>, he said this would be the last one to be marked by the usual ceremonies, that he could not go on mourning for ever.

**Long-term reactions.** Talks about death frequently. Has signed consent form for brain to be used for research after death. Anticipates that parents (in 70's) will die soon. It is predicted that when his mother dies his behaviour will become very disturbed if not violent. He realises that her death could mean loss of family home. Talks of committing suicide when both parents are dead. (Previously, when depressed, made an attempt.) Hopes he will not live to old age.

**Religious beliefs.** Greatly influenced by Steiner philosophy. Firm belief in after-life in which he will have no disability and in which he will be able to do all the things he has not been able to do in this life.

**What helped?** Expert counselling and belief in after-life.

**DOROTHY**

**Age at time of bereavement** - 37.

**Described as:** dependent, requiring supervision in living and working, with occasional physical intervention; able to express preferences and to converse; some occasional speech; occasional anxiety; ritualistic and obsessional when distressed; passive; equable with occasional anger; unable to express feelings.

**In residential care at time of bereavement.**

**Relationship to deceased** (father): close and affectionate. Home visits (1 or 2 weeks) 4 times a year. Postal contact every fortnight.

**Death was anticipated**, and the bereaved knew that her father was ill. She had not gone home for the summer holiday.

**Who informed client of death?** Two members of staff. The one responsible for bereavement support speaking, the other unobtrusively present to observe reactions.

**Explanation of death.** Death was explained in same terms as that of her mother who died 3 years previously. Daddy's pain had stopped, he had died and was in heaven with Mummy. The cat was being cared for by neighbours.

**Immediate reactions.** Client apparently understood loss immediately. Said, 'Daddy'. Very quiet, and later heard talking in the accent she uses when re-living early memories.

**Later reactions.** Subdued for several days. On being questioned by another resident about forthcoming holiday said: 'I am not going home because Daddy has gone to heaven', without appearing upset. Showed signs of impatience when things could not be done immediately, and less talkative with staff. Irritability.

**Funeral and rituals.** Attended funeral accompanied by two staff members. She did not join in singing as she would normally when others are singing, but no other unusual reaction. Present at crematorium and committal. The service meant very little to her and she did not ask about the coffin. Visited family home and very much enjoyed talking with relatives and guests. Her brother sorted out records and mementoes for her to keep. On leaving said 'Dad wasn't home today.' Seemed to accept reminder that Daddy was in heaven with Mummy. On the way home was heard to say, 'When Dad's back from heaven, I will go home on the coach.'

**Supported by:** mature staff member who accompanied her to the funeral. Was regularly available and on call if not on duty.

**Long-term reactions.** Questionnaire completed before these could be determined. It is believed that the previous bereavement has given the client some understanding of death. It has been observed that she interacts more with staff and other clients than she did before her bereavement.

**ELIZABETH**

**Age** at time of bereavement - 20.

Described as: dependent, needing supervision in living and working. Communicates with ease, able to converse. Episodes of anxiety which can be resolved if reason is known. Frequently obsessional and ritualistic. Pinches herself. Challenging behaviour in response to certain words, objects, music - also the death of her brother. Very high mathematical ability - 'savant'. Also artistic.

**In residential care at time of bereavement.**

**Relationship to deceased** (brother): close and affectionate.

**How was bereaved told of death?** Stepmother explained that her brother was taken up to heaven because he had been poorly and also had a sore leg. He was no longer in pain and was happy now.

**Immediate reactions.** She wanted to know when it happened, at what time. Was angry because her brother had left her.

**Later reactions.** It was one week before she cried and realised she could not see her brother again. When contact with him would have occurred (she had gone home every weekend and holidays) she became depressed, aggressive, tore clothes, inflicted self-injury. Sleeping pattern changed. Destructive. Was prescribed medication for severe depression. Complained of headaches, stomach pains, a very sad feeling in her heart. Afraid of her own death. Nightmares centred on her brother and 'black hole in the ground' (grave). Questions centred on the 'black hole in the ground'. Dreamed that her father was forcing her to eat meat which was her brother's flesh. Asked questions about heaven. Spoke of hearse, coffin, graves.

**Funeral and rituals.** The family considered it unwise for her to attend.

**Supported by:** senior care worker who was available to counsel, listen and comfort.

**What helped?** Counselling by staff member who talked to her, explaining that heaven was a wonderful place. Asked her to look at the sky and see how peaceful it looked. Told her it was good to cry. Took her to church to light candles on her brother's birthday and 'talk' to him.

**Comments.** Bereaved has been able to offer reassurance to a client whose grandmother died and also to a bereaved member of staff.

## **FREDERICK**

**Age** at time of bereavement - 20.

**Described as:** moderately able. Can live and work with partial autonomy. Problems of motivation. Able to converse. Ritualistic in small things. Anxious if routine is disturbed. Verbal abuse if anxiety is acute. Otherwise, equable and passive.

**Living at home and holding an independent job in community at time of bereavement.**

**Relationship to deceased** (father): apparently distant.

**Previous bereavement.** Lost Grandfather whom he loved. Spoke about him, e.g. 'Would Grandad have been at the cricket match?'

**Death was sudden.**

**How was bereaved told of death?** Mother said, 'Daddy had a heart attack and the doctors could not help him to get well, so God took him to heaven to make him better.'

**Immediate reactions.** No emotion. Put soup down and said, 'Are you all right, Mum?' - 'Why can't Charles (foster brother) come home and be head of this family?' - 'I don't want a step-father.' Understood his loss immediately. Reacted by fulfilling father's tasks such as coal carrying, walking the dog and cleaning the car.

**Later reactions.** Followed normal routines. Watched father's cricket team as usual, sitting at tea with the cricketers as though father still present. Blinked back tears when looking at father's photograph. Accepted mother changing her seat at table (taking father's chair). This was surprising as normally fiercely resistant to change. Took mother's hand when going to church a week after father's death. Normally would not have walked with her. Became more responsive to mother, helping with household tasks not previously undertaken, such as cutting the grass. Did not express grief verbally. After one year took keen interest in mother's male friends, expressing regret if relationship broke down.

**Funeral and rituals.** Present at funeral and cremation. Smiled at congregation as he passed them.

**Supported by:** mother and father's closest male friend who took over some of the father's caring role such as taking him to football matches, buying him an electric razor.

**Resolution of grief.** Mother has tried to encourage him to speak of father but without success. He continually looks at family photographs, including those of early childhood. Has totally accepted his step-father - 'I will call you Dad when you marry Mum.'

**Duration of grieving process:** 2 years.

**What helped?** Support of father's friend in ensuring continuity of normal activities.

**HARRIET**

**Age at time of bereavement - 34.**

**Described as:** dependent, requiring supervision in living and working; very limited language, able to express preferences. Able to express thoughts and feelings in writing, but only with mother. High level of anxiety and many fears (death, wars, natural disasters, accidents to parents). Usually reassurance and diversion can ensure she is settled and happy, but occasionally nothing can alleviate her anxiety; then challenging and compulsive behaviour can result.

**In residential care at time of bereavement.**

**Relationship to deceased** (grandfather): close and affectionate. Saw him most days when she lived at home. After she went to residential care, he stayed at the family home during her visits.

**Previous bereavements.** Grandmother died 13 years previously and client reacted with some disturbance. Two other deaths known to her. All deaths increase her anxiety about her own and parents' deaths.

**Death was anticipated.** She appeared to realise that her grandfather was failing well before he died. He was unable to visit the family home during her holiday and on her return staff noticed disturbed behaviour. Staff believed this resulted from a change in medication but parents were convinced it was her awareness of impending loss.

**How was bereaved told of death?** Key worker told her that Grandpa had died peacefully, not ill but very old. Three months before the death, mother broke her hip when Harriet was on home visit. On return to residential care she lost weight, exhibited challenging behaviour. Staff and parents agreed to delay telling her of grandfather's death until after she had seen her mother walking normally again and her behaviour (with extra staffing) had settled.

**Immediate reaction.** Accepted news calmly.

**Later reactions.** When parents visited, noticed she had scratches on hands and face. Tears when grandfather mentioned. Appeared grief-stricken. Later she wrote 'We are sad to think of Grandpa in his coffin.' Many times said that he was in his house and would come back.

**Funeral and rituals.** Because of distance and necessary delay in telling client of death (see above) she did not attend funeral.

**Supported by:** very caring key worker.

**Resolution of grief.** Later client wrote that she knew happy times with Grandpa would not return but that she remembered them.

**Duration of grieving process.** Six months before death and six months after it.

**Religious beliefs.** Influenced by attendance at Steiner school and Christian beliefs. Parents have explained that we meet our loved ones in the after-life.

**What helped?** Support from key worker who gave her extra attention. She shrinks from physical contact.

## **LARRY**

**Age** at time of bereavement - 3 (age when questionnaire completed - 20).

**Described as:** highly dependent, needing constant supervision and frequent physical intervention. Able to speak with difficulty; bangs his head to force words out (not yet able to speak at time of bereavement). Panic attacks. Obsessional, collecting objects which others would discard. Self-injury.

**Relationship to deceased** (grandfather): close and affectionate. Lived in the same house.

**Death was anticipated.** Larry was aware that his grandfather was in hospital during the fortnight before his death.

**How was bereaved told of death?** Mother said, 'Grandad has died and is not in pain any more.'

**Initial reactions.** Screamed on evening of funeral. Not long after funeral was humming parts of Beethoven's 9<sup>th</sup> Symphony, one of his grandfather's favourites.

**Later reactions.** Screaming at bedtime (his grandfather used to play violin and sing to him at bedtime). Humming Beethoven. Seemed to be in pain. Prone to infections, anxiety, hyperactivity.

**Funeral and rituals.** Not present at funeral but was taken to the burial by a neighbour. On later occasions helped to tidy the grave and waved goodbye.

**Resolution of grief.** Bereaved used to speak of 'Grandad at the cemetery,' but now no longer mentions him.

**Anniversary of death.** Anxiety around time of anniversary of death, but this also was the date of Larry's first visit to the mental handicap hospital where he now resides.

**Long-term reactions.** Wanting to die/afraid of dying.

**Comments.** Mother describes Larry's life as a series of bereavements: losing his grandfather (at age 3), sent by Local Authority to weekly boarding school 25 miles distant from his home (at age 7), losing father through failure of parents' marriage, admitted to permanent residence in hospital (at age 12). Is not allowed to visit home as the staff say that he is 'too attached' to it. Nor is his grandmother, of whom he is fond, allowed to visit him. He cannot listen to Beethoven's 9<sup>th</sup> Symphony as it makes him feel 'too sad'.

## **MALCOLM**

**Age** at time of bereavement - 28, father; 31, mother.

**Described as:** moderately able. Can live and work with partial autonomy. Extremely chatty. High and frequent anxiety. Obsessional, especially about antiques and china. Relates well to elderly females. Occasionally depressed, but changeable moods. Passive, tends to laziness.

**In residential care at the time of bereavement.**

**Relationship to deceased:** ambivalent towards father; close and affectionate with mother.

**Death was anticipated** in both cases and the bereaved knew they were ill.

**Immediate reactions when told of deaths.** Disbelief with father, anxious about his not really being dead saying, 'Promise me he is really dead'. Soon afterwards sought reassurance about his mother's health. When told of his mother's death, he said, 'Oh, really?' It took two or three days for him to realise that he had suffered a loss. He then said, 'I miss her.'

**Later reactions.** Could talk about his father's death. Of his mother, he said 'I miss her.' After her death he became very dependent on staff. Marked increase in anxiety with related hyper-ventilation. Frequently expressed a sense of loss, particularly about home visits and being spoiled by her. Became very withdrawn on the first Mother's Day after his mother's death when he realised there was no point in sending a card.

**Funeral and rituals.** Understood significance of rituals. Father's funeral was a 'social event' for the bereaved. Attended cremation also. Exhibited no sense of loss. Attended mother's funeral and cremation. Bought flowers and laid them on coffin. Was very involved and expressed sadness at each stage, though not weeping. He was able to share feeling with other, older relatives.

**Supported by:** mother (after father's death). Principal of residential service (after mother's death).

**Resolution of grief.** Adjusted to loss of his father in less than a year. As the questionnaire was completed soon after the death of his mother, it was difficult to reach conclusions about resolution of grief. Still says, 'I miss her' and 'I haven't anywhere to go now.'

**What helped?** Encouraging bereaved to talk about the deceased and a concerted effort to ensure that staff were available to offer support.

## **MATTHEW**

**Age at time of bereavement** - 31.

**Described as:** moderately able, capable of partial autonomy in living and working. Able to express feelings and converse easily, but rarely initiates conversation. Will always try to steer conversations in direction of his own interests, i.e. past personalities in his own life or 1960/70's celebrities. Anxiety deriving from over-hearing conversations which he assumes are about himself. Rare challenging

behaviour directed at mother or people who remind him of her. Lack of confidence, cheerful at times, moody at others.

**In residential care at the time of bereavement.**

**Relationship to deceased** (father): ambivalent.

**In what terms was the death explained?** Client cannot remember and relevant staff member has departed.

**Immediate reactions.** Very matter-of-fact.

**Later reactions.** Effects of bereavement unclear to staff. Bereaved is very matter-of-fact, referring to the deceased as 'My late father who's dead now.'

**Funeral and rituals.** Bereaved did not attend funeral on grounds that it would be too difficult for the mother. At the express request of his mother, the bereaved has not been permitted to visit the memorial stone. The client has acquiesced, not wishing to upset his mother.

**Resolution of grief.** No reference is made to deceased by client. If someone else initiates the subject he refers to the deceased as 'My late father who's dead now.'

**ADDITIONAL CONTRIBUTIONS** (Illustrations of 'inappropriate reactions')

**Bereaved:** A 13 year old boy (Asperger's Syndrome)

Parents were separated but the father maintained close contact with the boy. The father died suddenly and the boy returned to school on the following Monday telling staff that on the previous Saturday 'two sad things had happened'. On the previous Saturday:

1 His father had died.

2 Crystal Palace had lost their match.

Since then he has spoken about his father's death in a very matter-of-fact way, with no apparent awareness of any emotional implications.

**Bereaved:** A 16 year old girl (autistic with severe epilepsy)

When the bereavement occurred, she was living in a residential school. Her father died suddenly and her mother came to the school to inform her. She replied, 'That's nice that daddy's gone to heaven.' Later when shopping with her mother, she said, 'Oh, that's sad. You won't have to buy daddy's tea now.'

**References and other useful reading - bereavement**

Below is a list of books and articles used in the compilation of this document. Because people with autism may undergo reactions similar to those of children

without learning disabilities, a number of books on the effect of bereavement on children are included. Prices may need to be confirmed before ordering for purchase. The starred items are particularly helpful for those supporting bereaved people with autism.

### **Books and Pamphlets**

Brotchie, Jane, *Help at Hand, the Home Carers' Survival Guide*. Bedford Square Press, London, 1990. £6.95 paperback.

A very helpful book for anyone caring for another person at home, it includes useful and practical advice. The last two chapters, 'Death and Bereavement' and 'Resuming an Independent Life' offers useful advice to carers who have lost the person cared for, both on coping with the grieving process and on coming to terms with a different kind of life.

Brown, Alan, Editor, *Religions, a Study Course for GCSE*. Longman, 1988.

The authors are Alan Brown, John Rankin and Angela Wood. The articles on Judaism, Christianity, Islam, Hinduism, Buddhism and Sikhism cover history, beliefs, rituals, festivals, scriptures and worship.

\*Consumers' Association, *What to Do When Someone Dies*. Consumers' Association and Hodder and Stoughton Ltd., October, 1991. £9.95 paperback.

Obtainable from Which Bookshop, 359-361 Euston Road, other bookshops, or Subscription Department, Consumers' Association, PO Box 44, Hertford X, SG14 1SH. This is a more detailed guide than the DSS/COI publication (below), which should be used together with it.

\*DSS and COI, *What to Do After a Death*, Leaflet D49 from October 1990. Free of charge. Obtainable from local Department of Social Security or from: DSS Leaflets Unit, PO Box 21, Stanmore, Middlesex, HA7 1AY.

A step-by-step guide including forms required, registration, funeral, burial or cremation, disposition of property and possessions of the deceased and help for the survivors.

\*Hollins, Sheila and Sireling, Lester, *When Dad Died*. NFER-NELSON, 1991. £150 plus VAT.

This publication can be used as the basis for a training course for staff or as an aid to individual carers to enable them to support bereaved people with learning disabilities. It provides background information, exercises and discussion points to help carers develop appropriate skills and work cards to help the bereaved to understand what is happening and to encourage them to explore and express their feelings.

Krementz, Jill, *How it Feels When a Parent Dies*. First published by Alfred A Knopf, Inc. USA, 1981. Published by Victor Gollancz Ltd. 1983.

Eighteen children of different ages and cultural backgrounds speak of their experiences and feelings when a parent died. The reactions are varied, but many shared feelings of shock, confusion, anger and isolation.

\*Oswin, Maureen, *Am I Allowed to Cry?* Human Horizons Series, Souvenir Press, London and Canada, 1991. £7.99 paperback.

The author was one of the first to recognise the need for understanding and support of people with learning disabilities when they are bereaved. Based on years of research, this book cites many case histories to illustrate the devastating effects of insensitivity towards those undergoing the grieving process. The last chapter includes practical advice for staff training, the management of bereavement, and planning for bereavement by service providers, carers and local authorities.

Oswin, Maureen, *Bereavement and Mentally Handicapped People*. Kings Fund Report (KFC 81/234), December, 1981. 75p incl. p&p.

A short report establishing the principles which should be observed by those supporting bereaved people with learning disabilities and giving practical advice for those offering this support.

Parkes, Collin Murray, *Bereavement, Studies of Grief in Adult Life*. Pelican Books, London, 1975. Second edition, reprinted 1988. £5.99 paperback.

Based on many years of research, this is one of the standard works on bereavement. It is of value both to the bereaved and those who wish to help them.

Philpot, Terry, Editor, *Last Things, Social Work with the Dying and Bereaved*. Reed Business Publishing/Community Care, 1989. £5.95 paperback.

The subjects covered include working with bereaved families, terminal care teams, teamwork in the community, running a bereavement service, the future of the hospice, and death and bereavement in residential care. The book also includes a chapter by Maureen Oswin (see above) on bereavement and people with learning disabilities. Practical advice is given on the management of various types of bereavement and the terrible costs of mishandling death and bereavement are not minimised.

Pincus, Lily, *Death and the Family, the Importance of Mourning*. Faber and Faber, London and Boston, 1976. Paperback, 1981.

The material for this book was collected during the author's career in family therapy at the Tavistock Institute of Human Relations. Many of the case histories illustrate how bereavement has been complicated by problems in family relationships. The author was ahead of her time in advocating preparation for death and bereavement as part of education for life.

\*Sanctuary, Gerald, *After I'm Gone, What Will Happen to My Handicapped Child?* Human Horizons Series, Souvenir Press, 1984. Revised edition, 1991. £8.95 paperback.

The author was a former legal adviser for MENCAP. His book is an excellent guide for those wanting to provide for their family member with learning disabilities after their own deaths. A great deal of useful advice is offered on benefits, services, wills and trusts.

Schaeffer, Dan and Lyons, Christine, *How Do We Tell the Children?* Newmarket Press, New York, 1988.

This is a very useful step-by-step guide to talking to children about death and helping them to cope with the bereavement process, based on more than 25 years' experience by Dan Schaeffer as a funeral director and counsellor to bereaved children.

\*Staudacher, Carol, *Beyond Grief, a Guide for Recovering from the Death of a Loved One*. Human Horizons Series, Souvenir Press, 1988. £7.95 paperback.

This book is directed mainly towards the bereaved, enabling them to understand their own reactions and suggesting how they can find help. For the purpose of this document, the chapters on surviving loss during childhood, getting help (which includes suggestions for running a support group) and helping those who grieve, are particularly useful.

Stickney, Doris, *Waterbugs and Dragonflies, Explaining Death to Children*. Mowbray, 1982. Reprinted 1990. 95p.

This book is highly recommended for children by a number of specialists in bereavement counselling. An analogy is drawn of waterbugs' life under water as man's time on earth and their emergence as dragonflies in the sunlight as man's life after death. The booklet contains advice for parents and suggested prayers.

\*Ward, Barbara and associates, *Good Grief* (1), exploring feelings, loss and death with over 11's and adults. Third edition, 1991. £25 plus £3.25 p&p. *Good Grief* (2), exploring feelings, loss and death with under 11's, 1989. £25 plus £3.25 p&p. Both obtainable from Good Grief, 19 Bawtree Road, Uxbridge, Middlesex, UB8 1PT.

There is some overlap of material in the two packs. Exercises and projects are suggested which can help children to understand the various aspects of the life-span, death and bereavement. The structure of the packs enables them to be used not only as teaching materials but also as a means for those in the caring professions to explore losses in their own lives.

\*Wells, Rosemary, *Helping Children Cope with Grief, Facing a Death in the Family*. Overcoming Common Problems Series, Shelden Press, London, 1988. £3.50 paperback.

This book offers useful advice to anyone who wishes to help a child to cope with grief. There are chapters on terminal illness, unexpected death, the surviving parent, death of a sibling and school and religious attitudes. The last chapter is concerned with how childhood bereavement affects adult life.

Wertheimer, Alison, *A Special Scar, the Experiences of People Bereaved by Suicide*. Routledge, London and New York, 1991. £10.99 paperback.

Based on interviews with fifty bereaved people, this is the first book in Britain to examine the effects of suicide on survivors. The chapter on meeting the needs of survivors offers practical advice, and an appendix gives information on organisations which can help them.

\*Worden, J William, *Grief Counselling and Grief Therapy*. Routledge, London and New York, 1983. Reprinted 1988. £5.95 paperback.

This is a practical guide for all those wishing to help bereaved people. It offers a clear analysis of the grieving process and shows how to help the bereaved to accomplish the 'tasks of mourning'. It explains how the acute problems arising in bereavement are recognised and how appropriate support can be given.

### **Articles**

Brelstaff, K, 'Reactions to Death: can the mentally handicapped grieve? Some experiences of those who did.' *Teaching and Training*, Spring, 1984. 10-17.

Carr, A T, 'Dying and Bereavement', Chapter 7 in Hall, John, Editor, *Psychology for Nurses and Health Visitors*. British Psychological Society and MacMillan Publications Ltd., First Edition, 1982. Reprinted, 1988.

Day, Kenneth, 'Psychiatric Disorder in the Middle-Aged and Elderly Mentally Handicapped'. *British Journal of Psychiatry*, 1985. 147, 660-667.

Emerson, P, 'Covert Grief Reactions in Mentally Retarded Clients'. *Mental Retardation*, December, 1977. 46-47.

\*Kitching, Nicola, 'Helping People with Mental Handicaps Cope with Bereavement: a Case Study with Discussion'. *Mental Handicap*, Vol.15, June, 1987. 60-65.

\*McLoughlin, I J, 'Bereavement in the Mentally Handicapped'. *British Journal of Hospital Medicine*, October, 1986. 256-260.

### **References - autism**

Ellis, Kathryn, Editor, *Autism, Professional Perspectives and Practice*. Therapy in Practice Series, No.17, published by Chapman and Hall in association with the National Autistic Society, 1990. £9.95 plus 75p p&p.

(Quotation from: Brown, Wendy, Chapter 2: 'The Early Years'.)

The National Autistic Society, Parent and professional partnership in caring for adults with autism in National Autistic Society and affiliated society establishments. Code of Practice Procedures, Document No.1, NAS, 1990.

The National Autistic Society, Self-advocacy in National Autistic Society and affiliated society services for adults with autism: a change in the balance of power. Code of Practice Procedures, Document No.2, NAS, 1992.

### **Useful addresses**

#### **The Compassionate Friends**

6 Denmark Street  
Bristol BS1 5DQ  
tel. 01272-292778

A self-help organisation of bereaved parents offering friendship and understanding to other bereaved parents. The Bristol Office will put enquirers in touch with other parents in their area. (See Shadow of Suicide Group.)

#### **CRUSE Bereavement Care**

CRUSE House  
126 Sheen Road  
Richmond  
Surrey  
TW9 1UR  
tel. 0181-940-4818

A national organisation offering to help all bereaved people through its national office and local branches. It offers individual counselling, social meetings and advice on practical matters relating to bereavement. Whenever possible enquirers are directed to their local branch. If there is none, the Head Office has counsellors available to answer letters and talk on the telephone. They have a comprehensive publications list of books and leaflets which can be ordered from CRUSE House. Fact sheets on practical matters are available to CRUSE members only.

#### **MENCAP Bookshop**

123 Golden Lane  
London EC1Y 0RT  
tel. 020 7454 0454

The bookshop provides a list of books on bereavement obtainable from the above address, together with a list of addresses from which help can be sought.

#### **The Samaritans (Central Office)**

17 Uxbridge Road  
Slough  
Berkshire SL1 1SN  
tel. 01753-532713

(Local branches are listed in the telephone directory.)

A national service offering befriending to anyone feeling desperate, lonely, suicidal, or going through a personal crisis such as bereavement.

### **Shadow of Suicide Groups (SOS)**

A sub-group of The Compassionate Friends for parents of children who have taken their own lives. The SOS Group can put parents in touch with others similarly bereaved.

There are also local suicide bereavement groups in Belfast (CRUSE), Croydon (Samaritans), Reading (CRUSE).

### **Humanist and Non-Religious Funerals/Cremations**

#### **British Humanist Association**

14 Lambs Conduit Pass  
London WC1 4RH  
tel. 0171-499-6641

#### **National Secular Society**

702 Holloway Road  
London N19 3NL  
tel. 0171-272-1266

These organisations will enable contact with the nearest officiant. It is usual to pay a fee and transport expenses.