


BROTHERS OF CHARITY SERVICES IRELAND

GOOD PRACTICE GUIDELINES ON BEREAVEMENT

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Signed			Bro. Alfred Hassett
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Ethos

'We are committed to working with people with an intellectual disability to claim their rightful place as valued citizens. Inclusion is a fundamental principle that underlies all aspects of our work. We believe in the intrinsic value of every person and we aim to further the dignity of all associated with your services'.

'We continue the Brothers of Charity Service' tradition of being open to the best contemporary influences. We want to be inspired by the most creative ideas And to ask how we give them concrete expression'.

The Brothers of Charity Services Ethos (2001), Going Forward Together.

1.0 Introduction

The Brothers of Charity Services endeavour to offer services/supports in local communities. This enables each person who is supported by our services to positively engage in the social and economic life of their local towns and villages and in doing so, develop a range of relationships that enhance their quality of life.

Our responses are based on the recognition of each person (who is supported by our service) as an individual, an equal citizen with equal rights and an absolute respect of that status. We, therefore, support each person to live their lives based on their own personal visions and choices, to identify and select their personal goals in life and to develop their personal plan to achieve those goals.

1.1. Principles of Care in Bereavement Work

There are no reasons to assume that persons with intellectual disabilities do not experience some process of mourning following a loss. Sometimes the process may be different from other people but this does not indicate a less significant experience.

People with intellectual disabilities have as much right as other people to be given consideration and support in times of illness and in preparation for the death and eventual loss of a relative or close friend.

Each person with intellectual disability is an individual and will grieve as an individual.

Not all grief reactions of people with intellectual disabilities will be complicated.

People with intellectual disabilities may express their emotions in a more direct and open manner than the cultural norm and this possibility should be viewed as positive and advantageous.

People with intellectual disabilities have the right to be understood and respected if they do not grieve for a loss that staff or family may assume is important for them but in fact may not be.

It is necessary to be aware of the effect of particular religious or cultural backgrounds in the grieving process and to respect such differences.

2.0 Guidance Statement

This document has been written in response to a growing awareness within our organisation of the need for all staff to respond in a sympathetic and therapeutic manner to experiences of deep loss, which occur amongst members of our community. The experience of death is regarded as a fundamental and inevitable one in all our lives. It can give rise to a multiplicity of conflicting emotions, and can have a significant effect on the ability of a community to maintain stability and harmony.

Recognition of the importance of maintaining the well-being and happiness of all members of this community has led to the realisation that our response to death should take the form of a planned and co-ordinated effort, in order to minimise potential ill-effects. This effort should not override the natural responses that the individual, the family, or the staff might make.

3.0 Purpose

The need to acknowledge the grief of our individuals in our service as a valid and authentic response to the experience of loss has only recently become the focus of discussion among service providers. Just as it is now regarded as 'normal' for people with intellectual disability to aspire to establishing significant personal relationships, the range of emotions associated with such relationships must also be regarded as a normal experience for people with intellectual disability.

Thus, grief, and the grieving process, are normal occurrences for every human being at some stage in his life, and the ability to deal with the inevitable sadness associated with loss depends to a large extent on the presence of a supportive circle of caring friends and relatives who encourage the grieving person to express feelings in a manner appropriate to that person's circumstances.

4.0 Scope

The focus of this document is not centred solely on the individual with intellectual disability, All members of our service communities - staff, family members, day attenders and residents, need support in times of grief and loss. It is the intention of this document to point to ways of helping everyone in our community to deal with grief in a manner which will ultimately lead to personal growth and deeper self-awareness.

This document is not presented as a set of rules, which must be followed in instances of bereavement within our service. Rather, its role is to provide guidelines within which each individual's situation may be respected as unique.

5.0 Legislation and other related policies

- Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013
- National Standards for Residential Centres for Children and Adults 2013.
- Good Practice Guidelines on End of Life Care, Brothers of Charity Services, Ireland.

6.0 Glossary of Terms and Definitions

Bereavement is the period of time after a loss during which **grief** is experienced and **mourning** occurs. The time spent in a period of **bereavement** depends on how attached the person was to the person who died and how much time was spent anticipating the loss. **Mourning** is the process by which people adapt to a loss.

7.0 Roles and Responsibilities

7.1 It is the responsibility of the local manager to ensure that these guidelines disseminated to and understood by all staff.

7.2 All staff are expected be aware of these guidelines and to follow them in situations of bereavement.

8.0 Process

The Context in which we Approach Bereavement

This document is concerned with stressing the vital need to recognise bereavement and grieving as part of a normal process of coming to terms with great loss. This process, the mourning process, affects different people in different ways. It encompasses a wide range of reactions - emotional, cognitive, spiritual, behavioural and physical. The emotions experienced, the environmental factors mitigating the effects of loss, the behaviours manifested, and the length of time it takes to come to terms with such loss differ in degree, quality and intensity for each person.

Individuals, who may have difficulty communicating their feelings, may develop maladaptive behaviours which signify an internal struggle to come to terms with their loss. Instead of regarding such behaviours as abnormal, it is necessary to view them as indicators of unresolved grief and to attempt to find ways of helping the person to express the emotions which are provoking such behaviours.

Many individuals do not express emotions at the time they are bereaved, often leading to the conclusion that they are unmoved by the experience. It should be borne in mind that there is the possibility of a delayed grief reaction, giving rise to such behaviours, which may arise a number of years after the actual bereavement.

Awareness of the life history of the individual and sensitivity to his/her changing needs are essential in helping him/her to accomplish the tasks inherent in the grieving process.

8.1 Preparation for Loss

An individual's ability to cope with any crisis depends in great measure upon their preparation for it. As part of their right to share in normal experiences and to be helped to manage their own feelings they should be given every opportunity to prepare for loss and death. This could include ones admission to the service or other life changes for which people are well or ill prepared.

Opportunities should be taken to explain death factually and simply as part of the life cycle, using everyday examples, e.g. dead plants, insects, TV characters, etc. It is

important to help the person with intellectual disability to prepare for the losses of everyday life so that, having coped with these losses, such as family visits ending, staff leaving, etc., they may be helped to cope with greater bereavement.

Families are encouraged to prepare for the future welfare of the person with intellectual disability following the death of family members. Staff will be able to assist families with advice and guidance regarding measures that will help the person with intellectual disability to cope when bereavement occurs.

8.1.2 Anticipated Death

When death is anticipated it is helpful to make the person with intellectual disability aware of the seriousness of the illness and the approaching death of the relative or friend.

Agreement should be reached between family and staff as to how the news of an impending death should be broken. Common language should be agreed upon. The person should be told in simple language what is happening, allowing time for questions. They may need to hear the story again and again. Words such as 'death' and 'dying' should be used, to avoid confusion later. Staff may have to lead the conversation in many situations. Staff should also be aware of the possibility of self-criticism and self-blame and should be prepared to reassure the individual that the death is nobody's fault.

8.1.3 Visiting the Dying Person

It is helpful for the person with intellectual disability to visit the dying person and to say goodbye, thus helping him/her to accept the finality of death.

Careful preparation for the visit should be made so that the person with intellectual disability knows what to expect. The visit need not be a long one. The staff accompanying the person also needs to feel at ease when visiting someone who is terminally ill.

8.2 Breaking the News of a Death

The news of a death should be told slowly and honestly.

A simple factual description of what has taken place should be given, using the correct language associated with death. Words such as 'dead', 'dying' and 'died' have only one meaning. It is necessary to avoid the confusion of euphemisms such as 'gone to sleep' or 'passed on', which may be misleading.

8.3 When an Individual in a Residential Service Dies

Where feasible all residents in the house should be told together, sitting down as a family. Each individual will react differently and will need to be treated individually.

All staff working in this household should be aware of when the news is broken so that they can anticipate possible reactions.

When a colleague of a person with intellectual disability has died, families should be contacted and made aware that a death has taken place in day service, work or home.

Apart from immediate staff members, as many staff members as possible should be made aware that a bereavement has taken place, so that even chance encounters with the bereaved person serve as opportunities to sympathise with them, and to discuss the bereavement if they so wish.

Families should be told of the death of their relative while in our care quickly, accurately, and, unless circumstances prevent this, in a face-to-face meeting. Ideally, the family should be visited by a familiar member of staff and a member of the management or support team competent in offering the necessary support and advice required. Those informing the family of the death should be prepared for a range of possible grief reactions, which may include guilt or anger. While the family's preferences with regard to funeral arrangements must be respected, partnership in such arrangements should be offered to them.

8.4 Informing a Person with Intellectual Disability of the Death of a Family Member

Agreement should be reached between those most closely associated with the person as to who should break the news. Ideally, this should be someone who has a close and trusting relationship with them. This may be another family member, or a member of staff, or a close family friend.

All immediate staff members, and as many other members of staff as possible, should be made aware of the bereavement.

A natural instinct is to protect the individual. Honesty and simplicity are the preferred approaches, with consequent openness to possible reactions. Certain details may be regarded as unnecessary or disturbing but agreement must be reached between those most directly involved with the service user regarding the extent of the information imparted. Such consistency averts the risk of possible confusion afterwards.

Situations such as this place extra stress on the coping resources of staff and families, and immediate support from the service may be required.

8.5 Visiting the Body

Viewing the dead person assists the grieving process, but it may be a distressing experience. There are some situations where seeing the body can be a disadvantage, if, for example, the body has been badly damaged in an accident or a fire.

If the person has died at home or in a hospital, it may be less distressing if the body is still in bed when the individual visits. It may be helpful if the situation is described to them in simple terms beforehand (e.g. the eyes may not be closed).

If the dead person is in a hospital, care should be taken to ensure that medical equipment is removed to allow easy access to the body.

While gentle encouragement to touch the body may assist the eventual grieving process, this should not be forced. The person accompanying the individual may feel comfortable in demonstrating that it is appropriate, for example, to touch the dead person's hand. However, in instances where this would cause discomfort to the

person or his/her companion touching the body should not be regarded as an essential task of the visit.

The person should be given an opportunity, in consultation with the family, to see the body earlier in the day prior to the removal. This is often done with the support of staff that is familiar to the person and his family.

If the person is going to visit the body in a mortuary, access to the mortuary should be ascertained beforehand, particularly if wheelchair access is required.

A simple explanation of what to expect should be given to the person e.g. for example, the dead person will feel cold.

8.6 Going to Funerals

The person should be afforded every opportunity to attend and be part of funerals and other rituals surrounding death. On occasions when parents/relatives express the wish not to have their family member attend, the parent/relative may need support in recognising the importance of the individual's participation. This may be facilitated by the person visiting the body, maybe privately accompanied by staff with some family member prior to the removal and again being supported by staff at the funeral mass.

Relatives should be encouraged to keep the staff informed of the funeral arrangements.

The person's wish to attend part or all the service should be respected.

Staff have a particular responsibility to make themselves aware of procedures particular to the deceased person's religion.

In situations where other individuals wish to express their sympathy by attending the funerals of their peers' family members, they should be encouraged and facilitated to attend.

Transport arrangements to the funeral should be made with sensitivity to the grief of the person and other family members. Where feasible, small groups of people should accompany the individual in ordinary cars rather than transporting a large group of service users by minibus.

8.6.1 Cremations

As more people opt for cremation, it is advisable that staff or a family member explains this process to the person with intellectual disability.

8.7 Post Bereavement Support

Following the death, a member of staff should take responsibility for the support of the individual. This person should have a good relationship with the person and should feel comfortable talking about death. This may include being present with the person, being aware and acknowledging their sadness and supporting them in their grief. The process of grief varies from one individual to another. Sometimes there may be a delayed reaction or unexpressed grief may manifest itself in inappropriate behaviour. The person may require specialist support during this time.

Staff who feel inexperienced in giving support should inform their line manager of their concerns.

This bereavement support worker need not necessarily be a member of their usual care team, but should keep all staff that comes in contact with the bereaved person up-to-date on his/her reaction to the bereavement.

8.7.1 Bereavement Counselling

Not everyone who is bereaved requires bereavement counselling. Possible indicators of the need for such counselling are:

- Challenging behaviours not usually typical of the individual in question.
- Pining and expression of extreme loneliness.

Close monitoring of the person's grief reaction is necessary to determine whether special intervention in the form of bereavement counselling or group work is necessary. Staff may discuss at MDT meeting and request a review if a person is presenting with chronic grief reactions or related behaviour problems.

8.7.2 Follow Up with Families following the Death of a Relative

After the death of someone who is close to an individual, particularly a family member, staff may find that they are in close contact with the remaining family members who are also mourning the deceased person. Staff should be prepared to offer support to the family or refer to a primary contact person, e.g. social worker.

8.7.3 Follow Up with Families following the Death of a Person with an Intellectual Disability

Post-bereavement support to families may take many forms, such as practical support, e.g. advice regarding obtaining the death certificate, the cost of funerals, the management of the person's savings, and personal effects. An invitation to call to the person's work or living situation again.

8.8 Bereavement Work with People who have a Severe Intellectual Disability

While the concept of death may be difficult or impossible for a person with severe intellectual disability to fully comprehend, they may be aware of the absence of significant people in their lives. Staff need to be vigilant for signs of distress and anxiety, particularly in individuals that are unable to express such emotions verbally.

Non-verbal cues need to be interpreted appropriately, and the possibility of the presence of a grief reaction needs to be addressed by the care team associated with the individual in the same manner as was previously recommended for individuals with higher levels of ability. However, this may not manifest itself for several months or even years.

8.9 Admission to a Residential Service following the Death of a Family Member

Care needs to be taken to reduce, to the greatest possible extent, the traumatic effects of admission to a residential service following bereavement.

Where a residential placement is deemed necessary, the Policy on Applications for Services/Supports, Transfers and Withdrawal of Service/Supports should be followed.

If possible, in the event of anticipated death, a transition plan will be made to support the individual with their future residential needs

Following admission, family members should be encouraged to visit and as much as possible maintain contact with original home.

When entering a residential service the person should be able to bring personal belongings, photographs and other mementoes from home and should be given somewhere safe to keep them.

Written profiles on prospective individuals, particularly those with severe disabilities and/or speech problems, would be very helpful to staff in assisting the person to adjust to his new environment. Information such as likes and dislikes, fears, favourite foods, music and leisure activities, the names of particular friends and close relatives, as well as details of the person's normal daily routine should be included in the profile. Life Storybook could also benefit a person in sharing information with others to help in development of friendships/relationships with others

Every effort should be made to facilitate the person to maintain contact with special friends, former neighbours, or staff and peers in previous work placements. If possible, where a day attender is admitted to a residential service within this service, he/she should continue to attend his/her familiar day service.

No person should have to endure a number of changes of residence within the service following bereavement.

One member of staff should take a particular interest in the newly admitted resident, to reassure and support him through the adjustment period.

In any multidisciplinary assessment carried out within a twelve month period following bereavement, the issues relating to the bereavement should be taken into consideration.

A review of progress should take place one month after admission, and regularly for a period of twelve months thereafter, to assess the person's level of adjustment. The responsibility for organising this review rests with the service area manager(s).

9.0 Review

A review of this guidance document will be carried out every 3 years unless for example, an audit, serious incident, organisational structural change, scope of practice change, advances in technology, significant changes in international best practice or legislation identifies the need to update this good practice guidelines document on bereavement.

10.0 References

Supporting People with Disabilities Coping with Grief and Loss. An Easy Read Document. SCOPE 2007 HREPSIME GULBENKOGLU.

Let's Talk About Death. A booklet about funerals for adults who have a learning disability. Down's Syndrome, Scotland.

Brothers of Charity Services Limerick Bereavement Pack 2015