

## Grief Among Individuals with Developmental Disabilities

Prepared by Alejandro Morales, LISW

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### Introduction

Grief is an experience that occurs after a person suffers a significant loss, when the individual is separated from another person with whom strong feelings of closeness and love have developed over time.

People with developmental disabilities develop close ties to other individuals and will experience loss at various times during their life. Like other individuals, they may experience the death of a loved one. They may also experience loss due to separations as a result of moving away from their families. In addition, it is not unusual for individuals with developmental disabilities to form attachments with their care providers, only to be separated from them by a change in the care provider's job situation. (Deutch '85)

Any of these experiences can cause feelings of loss that leads to a period of mourning. Unfortunately, individuals with developmental disabilities are frequently unprepared for dealing with their grief, and usually receive little or no assistance through the mourning process. They may be at risk for long-lasting behavioral and emotional problems as a result of the grief experience. (Wadsworth, Harper and Fowler, 1991) It is very important to understand and help individuals with developmental disabilities to go through the grieving process because they often have a hard time showing and dealing with their grief. People with developmental disabilities are kept from dealing with their grief by well-intentioned care providers, guardians and/or family members who wish to protect individuals from "upsetting events" (Seltzer). Care providers often assume that individuals with developmental disabilities have little or no awareness associated with this grieving process as it relates to the issue of "final" loss. Displays of grief often are misunderstood and thus discouraged, particularly when the emotional and behavioral expressions of grief are intense or very disruptive (Carder, 1987; Lipe-Goodson and Goebel, 1983). There are those who believe that it would be easier for individuals with developmental disabilities to accept the death of a loved one if that information were shared with them over a long period of time. It is also not uncommon for grief reactions to be mislabeled or disregarded because of the assumed lack of awareness of such issues in individuals with moderate to severe mental retardation.

All of these rationalizations make life easier for the care provider, but much more difficult for the individual with developmental disabilities. Inadequate or incomplete mourning may have several consequences, including denial of the reality of the loved one's death, the idealization of the loved one, a decrease in self-esteem, and feelings of guilt. If the individual does not progress through the task of mourning, these feelings of alienation, loneliness, and depression may continue, for years after the death of loved one (Deutch, 1985).

Grief refers to the multifaceted, intense internal and external responses (emotional, behavioral, psychological, and physiological) to perceived and observed losses, such as a death of close friend (Bowlby, 1950). Grief reactions may be felt in response to physical losses (for example, a death) or in response to symbolic or social losses (for example, divorce or loss of a job), Grief may be experienced as a mental, physical, social, or emotional reaction. Mental reactions can include anger, guilt, anxiety, sadness and despair. Social reactions can include feelings about taking care of others in the family, seeing family friends, or returning to work. Physical reactions can include sleeping problems, changes in appetite, physical problems, or illness.

The loss of a loved one is life's most stressful event and can cause a major emotional crisis. After the death of someone you love, you experience bereavement, which literally means, "to be deprived by death." Bereavement includes the process of coping and experiencing a response to a significant loss or separation. Bereavement becomes

apparent when the individual displays behavior that implies they are "upset" over the separation from a person, pet, object or situation (Harper and Wadsworth, 1993, p. 314).

Mourning is the natural process one goes through to accept a major loss. Mourning consists of the conscious, unconscious, and cultural reactions to loss. Mourning includes the process of adjusting the experience of loss into ongoing life. Mourning is also influenced by cultural customs, rituals, and society's rules for coping with loss.

### **Stages of Grief**

Each person's pattern of mourning reflects his or her unique way of viewing and dealing with that loss. Normally most people pass through five distinct stages of grief, according to Elizabeth Kubler-Ross (an expert on death and dying). These stages are:

1. Denial ("This is not happening to me.")
2. Anger ("How could she leave me like that? I hate her!")
3. Bargaining ("I'll be a better daughter/son if...")
4. Depression ("I don't feel like doing anything or seeing anyone.")
5. Acceptance. ("I have to get on with my life.")

Some people experience these stages in this order, but many do not. And some people grieve for different periods of time. Furthermore, developmental impairments complicate the grieving process because the individual may experience greater difficulties in expressing emotions, adapting to changes in relationships, and understanding the difference between life and death (Vredveld, R., 1985). The manner in which developmental disabilities impair the individual's understanding of death and the grieving is not well understood. Assumptions that equate "understanding" the finality of death with the ability to feel or experience grief and bereavement have only recently been questioned.

### **The Tasks of Mourning**

Worden (1982) identified four tasks that need to be resolved in order for an individual to successfully complete the mourning process.

#### **Task I. To accept the reality of the loss**

At first, there is a natural tendency to deny the reality of the loss to protect the individual from the emotional impact of the loss. If the denial continues over time it may become pathological, and prevent the individual from returning to a normal level of functioning. Thus, the first task of mourning is to realize that the person is dead or gone and will never return.

#### **Task II. To experience the pain of grief**

The emotional pain of grief is present once the reality of death or loss is accepted. People resist feeling pain and may go through great lengths to avoid it. Eventually people realize that no matter what distractions they create they do not escape the pain and only succeed in prolonging the mourning process. It is important that individuals with mental retardation be allowed to express their grief and be encouraged to talk about their loss (given their ability to talk).

#### **Task III. To adjust to an environment in which a loved one is missing**

After the death of a loved one, tasks that were performed by him/her must be assumed by others. Individuals will need to adjust to the loss of companionship, the emotional support and even the loss of activities that the loved one

performed for the individual. Accepting the reality that other people may need to assume important roles in their lives may be very difficult for many individuals with developmental disabilities.

#### **Task IV. To withdraw emotional energy and reinvest it in another relationship.**

A key issue during the final task of grieving is for a person to move on with their lives. This can be very difficult task because at first they may feel they are dishonoring their loved one. They will need to trust that they will not forget the ones who died and will remain in their hearts and minds forever. Individuals with developmental disabilities may need to be reassured that many other individuals care about them and are willing to be supportive of their needs.

In order for people to heal from a loss, each person will accomplish these four tasks in their own way. If persons do not accomplish these they run the risk of becoming "stuck" in grief. Unresolved grief can resurface later in life and be a significant cause of distress in their lives as well as to others close to them. Some people do not receive the help they need to heal from their losses. Individuals with developmental disabilities could benefit greatly from assistance that caregivers could offer them when they are experiencing a significant loss in their lives. Caregivers need to be aware that there are certain circumstances that are found among individuals with developmental disabilities. Again, people are individually different; that is, not all individuals with developmental disabilities will exhibit all of these characteristics nor have all of these experiences. Luchterhand and Murphy have summarized some ways in which individuals with developmental disabilities may differ from their peers in the general population. They include the following:

##### **Difficulties in learning or understanding (cognitive difficulties)**

Difficulty in learning or understanding is one of the major reasons why some family members and professionals do not talk about death to individuals with mental retardation. The cognitive abilities of individuals with developmental disabilities vary greatly from person to person. For example, it may very difficult to know how someone who has severe to profound mental retardation is experiencing loss. However, most individuals with mental retardation have mild to moderate cognitive disabilities. They will have emotions about a death and have the ability to understand and talk about this issue. They will benefit from assistance in learning about death, loss and the grieving process.

It is also critical for care providers to realize that individuals with mental retardation do not have to understand the concept of death in order to feel loss. It is the experience and subsequent grief about the loss, not whether individuals with mental retardation understand the concept of death, that should motivate care providers to provide help.

##### **Decreased or Altered Expression of Emotion**

Many individuals with developmental disabilities do not express their emotions in a manner that might be considered typical. Their faces and words may not reflect their true feelings. It is important for care givers to look for other indicators of their true feelings, such as their behavior, and to use nonverbal means of helping them express their emotions.

##### **Tendency to Respond in a Positive Manner**

Some individuals with developmental disabilities have a tendency to say yes to whatever question a person they are interacting with may pose (Sigelman, Budd, Winder, Schoenrock, and Martin). They do this because over the years they have developed a desire to please people as a way to be accepted socially.

##### **Behavior (Rather Than Words) as a Sign of True Feelings**

For some individuals with developmental disabilities, a change in behavior may show us that they are upset more than what they say. In a study where individuals with mental retardation developed uncharacteristic behaviors such as verbal or physical aggression or extreme withdrawal, it was reported that in about half of those cases the individuals had experienced a death or the loss of someone close (Emerson, 1977).

**Behavior to observe includes the following:**

- Have sleeping patterns changed?
- Have eating habits changed?
- Has work productivity changed?
- Is the person withdrawing from social activities?
- Has there been an increase in complaints of pain or illness?
- Has their personality changed?

**Often Family Members or Professionals Treat Them Differently Than Others**

People often try to protect individuals with developmental disabilities from the harsh realities of life and death. People with developmental disabilities do not live in a vacuum. Their lives will be affected by the death or loss of someone close to them. When they are treated differently because they have developmental disabilities, they may have additional problems they have to deal with. They may have been left out of family gatherings and rituals surrounding death, such as funerals. Then they may need help to manage their feelings of isolation or anger at being left out, as well as their grief.

**Family Members Often Act as Reporters or Interpreters**

Family members or other caregivers can provide a valuable service by acting as a reporter to share important facts about the person's past history or as an interpreter to help others know what the individual with developmental disabilities is trying to communicate. However, there is a danger with this situation as well. The helper may misunderstand the person's feelings. This may be especially true regarding issues of grief and bereavement, since many helpers do not know the steps of typical grieving and are uncomfortable with the subject (Kloppel and Hollins, 1989).

It is important whenever a reporter is used, to ask detailed questions about the person's reactions rather than just obtaining information about the helper's beliefs. Questions to ask might include the following:

- How has he/she responded when staff have talked to him/her about the person who died?
- What has the person done or said that makes the staff think he is coping well or not coping well?
- Has he/she acted in ways that are usual for him/her?

**Lack of Social Support**

In general, individuals not have mental retardation with developmental disabilities have fewer social support systems than people without developmental disabilities. Most do not marry or have children; some have limited opportunities to develop friendships. Staff turnover in agencies that provide residential support is often high. The Relationships that are the closest in their entire lives may be their parents. Thus, grieving the death of a parent for them may require much more time, effort, and support than for most people.

**Sense of Connection to Others That Is Not Obvious**

Some family members or professionals are surprised at the intensity of the grief expressed by someone with developmental disabilities because they did not feel that the relationship had been a close one. Remember the relatively small social circle of individuals with developmental disabilities. As adults they may fear

being left alone in the world without relatives. Also, relationships with adults with developmental disabilities may not involve the same give-and-take when compared to other relationships, yet to the person with developmental disabilities the relationship is a very important one.

### **History of Multiple Losses**

Be aware that an older adult with developmental disabilities have experienced multiple losses over the years. They may had numerous residential transitions, losses of friends with whom they had lived, staff turnover, and changes in jobs and vocational settings. If a person dies that was the primary caregiver of the adult with developmental disabilities, many losses may occur all at once (Kloeppel and Hollins, 1989). Sometime a recent loss reawakens feelings related to a loss they experienced earlier in their life. Grief can become more complicated when someone experiences several losses. The bereaved individual may be overwhelmed and not be able to finish the "grief work" needed to heal unless they have help.

### **Lack of Resources**

Individuals with developmental disabilities may not know how to deal with their losses. They may not have been around death before or had training that would enable them to understand better what occurs. They often lack the resources or abilities to carry out actions that they feel would be helpful.

### **Uncertain Future**

Most individuals with developmental disabilities need some form of lifelong support. If that support had previously been provided by the person who died the future may appear to them to be very frightening. Whether the relationship between the person with developmental disabilities and the loved one was an obviously close one or a "hidden connection" the death can increase fear that others in the bereaved person's life will die soon or leave. This can help cause the person to feel that the world is unpredictable, out of control, and unsafe.

It is helpful to keep the above things in mind when supporting individuals with developmental disabilities. They may provide clues regarding why someone is behaving in a certain way, what emotions are being felt, and how one might assist.

## **Helping Individuals with Developmental Disabilities through the Grieving Process**

Some helpful guidelines have been developed by Charlene Luchterhand and Nancy Murphy that could very useful in helping most individuals with developmental disabilities through the grieving process. Given the fact that grieving is unique to each individual and the particular situation, care providers may want to consider the following guidelines:

### **Tell the Person That the Death or Loss Has Occurred**

Some people debate whether or not an individual with developmental disabilities should be told about the death of a person close to them. Luchterhand and Murphy believe that adults with mental retardation should participate as full citizens in the community. They then cannot be denied the opportunities to learn about life and death events that affect them intimately. To do so would be to not allow them the full range of human experiences.

Also, individuals with developmental disabilities will know that something is wrong; something will be different in their lives. No one provides transportation to visit mom in the nursing home. A new staff person arrives unexpectedly, and no one talks about the previous staff member who seemed to vanish. Their imagination might provide worse explanations than reality. "Mom doesn't love me anymore." "I did something wrong, so my favorite staff person is mad at me and won't spend time with me anymore."

Another reason for being open with individuals with developmental disabilities is that they will be prepared to cope with the loss if they learn about it in a direct way. For example, if the news of a death has been kept secret, it is natural that the bereaved person will believe that the loved one will return some day. Faulty or false information at the time of loss frequently will mean that people are not able to grieve consciously. They then will be at risk for more complicated grief reactions (Bowlby, 1980).

### **Suggestions for telling an adult with developmental disabilities about a loss of someone close.**

- Identify a person who is close or at least knows and is familiar with the adult with developmental disabilities to break the news about the loss.
- Carefully choose the initial statement and the setting where the person is told about the loss.
- Explain the loss in a way that maximizes the person's ability to understand.
- Do not worry too much if you happen to say something in a manner that wasn't perfect.
- Allow and Encourage the Person to Share His or Her Feelings.

Family members and other care providers may become upset by the amount and intensity of the emotion that is expressed by an adult with developmental disabilities. They may try to prevent a strong show of emotion such as crying or angry outbursts. It is easy to understand why someone might want to do this because it is difficult to watch another person grieve. Yet openly expressing the pain will help the person to recover. Usually the strong emotional responses will lessen over time. If grief responses seem overwhelming to you, than one should seek professional help for the person.

Sometimes individuals with developmental disabilities that experience the death of someone close to them may have an opposite response. They may appear calm and may not want to talk about the loss. This may be their way of coping with the loss but they have not realized the impact it will have on their life. It may take months before they realize the loss. Luchterhand and Murphy suggest that most adults with developmental disabilities would benefit from having someone who will initiate conversation about the loss. It is not a good idea, however, to force the person to loss with you about the subject. Instead, offer the chance to talk with you about it on several occasions over a period of time, at least several months.

### **Provide Reassurance That He or She Is Not Alone and That Others Are There to Help**

One reason people avoid talking about a death is because they do not know what to say or what to do. They feel helpless and know they cannot solve the problem. As a helper, you are not expected to solve the problem.

You can learn to comfort someone who is going through emotional pain. You can be there so that the person with developmental disabilities is not alone. You can listen, give a hug and/or hold a hand. You can do an activity that was done previously by the person that left or died. You can reassure him or her that someone will be there for them in the future. Help the bereaved person identify people to whom he or she might turn for help with various tasks.

### **Remember That the Grief Process Takes Time**

The length of time people grieve is individualized and lasts longer than most people expect. The bereaved person needs to learn to live without the loved one..

### **Be Patient with the Grieving Person**

Grieving persons often feel the need to tell and retell stories about their relationship with the person that is gone or died including details of reasons why it happened. This helps them "hear' or come to terms with the

reality of what has happened and to adjust to this new reality (Cook and Dworkin, 1992; Weizman and Kamm, 1985). "Retelling" is a normal part of grieving and being willing to listen non-judgmentally to multiple retellings can help the bereaved greatly at a time when their usual support may be getting tired or drifting away.

### **Learn from the Person Who is Grieving**

Hospice staff and others who work in the field of grief know that one of the important guidelines to remember in helping someone who is grieving is to learn from that person. They quickly learn to "walk beside" the grieving person, rather than assuming that they know what the person is feeling and experiencing at any given time or trying to "lead" him or her to a different state of mind. Each person's experience is unique.

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