Helping People with Disabilities to Cope with Grief and Loss

This month’s training focuses on grief and loss for people with developmental disabilities. This facet is often overlooked and understood by caregivers. The information is taken from a wonderful pamphlet called, “Supporting People with Disabilities Coping with Grief and Loss”. It is available at: [http://www.scopevic.org.au/griefLoss_web.pdf](http://www.scopevic.org.au/griefLoss_web.pdf). I urge everyone to check this booklet out. Not only does it contain this information, but there is another part that has pictures explaining death to people with disabilities.

Introduction

Grief is a normal human emotion or set of emotions that occur in response to a significant loss. It is a universal emotion and applies to all human beings regardless of their abilities or disabilities. Grief is our emotional response to loss. It can emerge as a result of death, bereavement or a multitude of everyday experiences related to loss in life. These losses can be actual or perceived. Actual losses can include the death of a loved one, or the loss of a significant relationship in one’s life. A perceived loss can include something that was hoped or planned for, that was never realized.

This booklet talks about a range of losses, but mainly focuses on feelings of grief and loss as it relates to the death of someone special for the person. Although grief is a universal emotion, the experience of grief is individual and unique. In other words, while there are characteristics of grief and bereavement that are common to most people, each person will experience grief differently. The life experiences a person has, along with some characteristics sometimes associated with disability can have an effect on how a person grieves, and also how others interpret their grief responses. The literature in this area is very limited, particularly in relation to grief issues for people with complex communication needs. However, there is certainly a shift in the way we view the grief responses of people with disabilities. Whereas it was once believed that people with disabilities were ‘protected’ from grief, there is now increased acknowledgment that people with disabilities also experience grief reactions. There is a clear and growing awareness that the capacity to grieve is not only based on our ability to understand the concept of grief, but also our ability to feel the loss incurred. In other words, the experience of loss and the subsequent grief can occur, regardless of our understanding of death. Our approach to supporting people with disabilities needs to stem from this notion of ‘experience of loss’ rather than just ‘understanding the concept of death’. Worden (1991), who has done substantial work in the area of grief and loss, suggests that grief consist of four dimensions, namely, feelings, thoughts, behaviors and physical sensations.

Feelings

Feelings associated with grief and loss may include:
• Sadness,
• Anger,
• Emptiness,
• Loneliness,
• Shock,
• Numbness,
• Confusion,
• Disbelief,
• Resentment,
• Denial,
• Frustration,
• Irritability.

Thoughts

Changes in a person’s thinking processes may include:
• Difficulty in attending or concentrating,
• Difficulty making decisions,
• Concerned and confused thoughts about self and others,
• Pre-occupation with the person who has died.

Additionally, the person may experience particular thoughts that may include:
• “It can’t be true”,
• “Why me?”,
• “Am I always going to feel like this”,
• “I will never get over this”,
• “I feel scared and lonely.”

Behaviors
Grief and loss can also be associated with changes in a person’s behavior and may include:
• Withdrawal,
• Physical aggression,
• Verbal aggression,
• Crying,
• Changes in eating and toileting,
• Changes in appetite,
• Loss of interest in activities,
• Sleep disturbance.

Physical Sensations
Grief and loss may also be associated with changes in body functions including:
• Shortness of breath,
• Pounding heart,
• Hypertension,
• Dizziness,
• Shaking,
• Sweating,
• Pain reactions,
• Tingling and numbness,
• Fatigue,
• Previous illnesses flaring up.

The Impact Of Disability On Grieving
People with disabilities are like everyone else. They may experience a range of losses through their lives, which might set grief reactions. There are a number of factors that can impact on the grieving of the person with a disability. Although we know that grief reactions are very individual and unique and differ from one person to the other, there are some characteristics that can be seen in some people with disability. These may relate to cognitive, communication and learning experience factors.

Cognitive Factors
People with disabilities present with a range of cognitive skills. Where a person has difficulties with learning or comprehension, others may draw assumptions about that person’s ability to deal with loss and grief. This may lead support people to think that the person with the disability may not have understood what has happened. They may also assume that the person does not feel the loss, or that they need to be protected from the truth, or that by not talking about the issue, the loss will be less obvious to them. However, it is important to realize that people with disabilities don’t need to have a full understanding of the concept of death to feel the loss. They may feel the loss by virtue of the fact that an important person in their life is no longer there. People can have varying degrees of understanding of loss. A person’s understanding can range from a ‘sense’ of loss, to a realization of the permanency of the loss, to a more abstract understanding about life and death. But regardless of where a person is on this continuum, the person is likely to feel the loss in some way.

Communication Factors
Some people with disabilities have complex communication needs. That is, they may be unable to use speech to meet their daily communication needs. They may rely, to varying degrees, on augmentative communication methods, like vocalizations, gestures, and facial expression. They may also rely on alternative communication systems. A person with complex communication needs may have difficulty expressing their emotions, asking questions and conveying information about grief and loss. Some people may show difficulty expressing negative emotions because over time they may have developed an attitude of trying to please others. They may not feel they have the right or the ‘permission’ to express negative emotions. For some people with disabilities, a change in behavior might be a better indicator of grief and loss than what the person communicates directly through speech or through other means. It is also important to be sensitive to any changes in eating or sleeping patterns, or interest or participation in activities and social interactions. These may indicate how the person is coping with the loss.

Learning Experiences
The life experiences of people with disabilities can make it difficult for them to deal effectively with loss and grief. Parents and staff may treat them differently. For example, parents and staff at times may try to shield them from the harsh realities of life with the fear that they may not be able to cope. People
with disabilities might have experienced multiple losses over time. They may have seen a number of friends or people they have known die. They may have also experienced ongoing staff turnover and changes in residential settings and living arrangements, many of which are beyond their control. If the person has a limited number of close relationships and social supports, the impact of these losses may be more magnified than would otherwise be the case. If the person who has died is the primary care giver, then the loss can be experienced at multiple levels. As a result of the death, the person with a disability may not only experience the loss of someone they care very much about, but potentially also experience major changes in their daily routine, living arrangements and financial circumstances. Hence, the loss may also trigger anxiety reactions about their own day-to-day living, care and future.

What To Do
Because each person and the way they grieve is unique, the kinds of supports and the assistance offered will also need to be individualized. However, there are some general guidelines that may be helpful to many people with disabilities who are experiencing grief.
Most importantly, inform the person openly and honestly that death has occurred. This may seem a fairly obvious idea, but is often overlooked, with the person often finding out through hearsay or other indirect channels of communication. If a person is not told about the death openly and honestly, then:
• The person’s ‘right to know’ has not been respected.
• The person is denied the opportunity to learn about life and death.
• The person is once again ‘shielded’ from bad news.
• The person is denied the opportunity to be part of ‘normal’ grief activities, such as attending the funeral.
• The person may perceive the loss, but not in an accurate way. They may comprehend the loss to be something different than what it actually is, and attach an interpretation of death that is much worse than the reality.

It is important, where possible, that someone who is close to the person with disability gives the sad news. This can help to ease the pain of hearing distressing news. There is no “good” way of telling a person about the death of someone close. Each individual and each situation is unique. People with disabilities will have different experiences in relation to death and loss. Some may have already experienced the death of someone close and might have dealt with it effectively. Others might have been protected from this concept. The knowledge you have of the person and your relationship with them will very much determine the manner in which you tell the person of the sad news. Some general ideas are:
• Tell the person that death has occurred.
• Explain the death with words that you think he or she will understand.
• Allow and encourage expression of feelings.
• Provide reassurance that the person is not alone and help is available.
• Provide company or space as requested.

General strategies to support people with disabilities deal effectively with grief and loss
Described below are some general strategies that are helpful to consider as you support people with disabilities to deal with grief and loss. These strategies may be helpful for many people, not just those with disabilities. As stated earlier all people grieve differently and their needs for support will be different. So it is important to remember that these strategies are to be used as guidelines only.

Encourage open and honest communication
Give explanations appropriate to the person’s level of comprehension. Make sure that you use words that the person can easily understand.
• Refrain from abstract explanations. Use clear, simple and concrete phrases.
• Use words that describe death in real terms. For example, “(the person) died” rather than “(the person) passed away”, or “(the person) has gone to a better place”, or “we’ve lost (the person)”. However, if the person has words that describe death in a way that is meaningful to them, based on their previous experiences, then these words can be used.

• Talk about the deceased, ask and allow questions. This gives the person the opportunity to understand that loss has happened, it also reinforces the idea that it is OK to talk about the death, while also giving the listener an opportunity to identify and address any inaccuracies in the person’s understanding of the death.

• Accept short conversations. Some people may not feel like communicating their thoughts at the time, or they may not know what to say. However, it is important for the person to know that they can talk about it at some later stage if they feel like it.

• Tolerate silences. Don’t be afraid of silences. They are a natural part of the listening process, and can also be useful in terms of giving the person a chance to collect their thoughts. Sometimes, the fact that you are there with the person may be sufficiently reassuring.

Encourage and allow expression of emotion

• Listen, rather than try to ‘fix’. Be aware that it is difficult to ‘take the pain away’. The person will need to work through this process themselves. The role of the support person is being there when needed.

• Don’t judge. Be aware that we all have our own set of values and beliefs. Particularly in relation to grief and loss, people can have a wide range of belief systems, such as varied spiritual beliefs, rituals and other ways of expressing grief.

• Reassure that it is OK to have a range of feelings. This is important in terms of normalizing different feelings, and also conflicting types of feelings, such as when someone experiences both deep sadness, but also anger toward the person who has died.

• Reassure that it is OK to cry. Crying is a normal human response to a significant loss, and can be useful as an emotional outlet.

• Validate the person’s feelings. Let the person know that you can see that they are experiencing emotional pain, and acknowledge that they are going through a difficult experience, but that also, they will work through this.

• Address fears and anxieties. Listen carefully for any specific fears, such as fear that the person themselves will die, or that their support needs will no longer be met, and reassure the person appropriately.

Help the person to understand the reality of the loss

• Talk about the deceased. It is OK and indeed healthy to talk about the person who has died, and this should be encouraged. However, be led by the person who you are supporting in this, and do not force this topic of conversation if the person is not ready or willing.

• Encourage the person to participate in the rituals (viewing, funeral, visiting gravesite etc.). Taking part in rituals can contribute to the person’s sense of belonging and connectedness, as well as helping the person’s own recovery from grief. However, this should always be presented as an option to the person, or their advocate. Do not force the person to attend a funeral or participate in other rituals if they do not wish to do so.

• Keep the reminders of the dead person present. This is important in terms of acknowledging and confronting the loss, but also as a reminder of the deceased person and their legacy. Once again, be led by the person, because concrete reminders can sometimes be profoundly painful, particularly in the early stages of grief. In these cases, you may wish to offer these reminders again at a later date.

Provide reassurance and support

• Be available, patient and accommodating. Grief is a complex emotion, and can take time to work through.
• Provide care, comfort and practical support. A sensitive and flexible approach to support will be required. Some times may be more difficult than other times, and the person may require extra support at these moments.

• Encourage routine activities. Routine gives a sense of stability at times of emotional turmoil.

• Encourage the person to minimize change. When a person has experienced significant loss, there is usually significant disruption to their life, so it is important to avoid any further and unnecessary changes.

• Discourage the grieving person from making major decisions. Because of the changes in thinking processes associated with grief, people can have difficulty in concentrating on all the relevant factors for making significant life decisions. If possible, delay big decisions for a time in the future.

• Provide continuity of support in different settings. Try to ensure that people are supported in their various environments and are given consistent messages across these environments.

• Encourage the person to use their local support networks. Talking with someone, such as a friend or family member, who knows the person well and who is familiar with the person’s circumstances is often the best and most natural type of support.

• Additionally, the person may be encouraged to communicate with others who they may not know so well, but who have been through a similar loss in their life.

• Support structures that are helpful for people with more complex needs who don’t have a formal communication system may need to draw less on strategies based on language and draw more heavily on environment based strategies. Strategies may need to focus on providing a sense of security, stability, comfort, routine and continuity for the person. They may also include relaxation supports, such as sensory activities, based on the person’s preferences that are conducive to a calm state and/or expression of emotion.

• Grief responses can sometimes be associated with challenging behaviors, particularly when a person’s communication channels are limited and they have difficulty expressing their grief in any other way. In this case, the involvement of a behavioral support practitioner (e.g., psychologist) may be useful. This person can explore the underlying functions of this behavior and develop strategies for addressing the challenging behavior.

• Offer seeking specialist services, such as counseling, to people with disabilities who display more complicated grief reactions. People whose grief reactions are of an intense or severe nature, take a significant period of time and impact on their daily functioning may require specialist and individualized support to assist them in dealing with their grief.

Creative ideas and activities to assist the person with disability through the grief process
Contained in this section are some ideas that have been found to be useful when assisting people with disabilities to deal with grief and loss. As stated earlier each person’s way of dealing with grief is unique and individual and so are their support needs. So it is very important that support people consider these ideas in the light of their knowledge of the person and what that person may wish. Once you feel the person is ready, some possibilities to consider and offer are:

• Creating a memory box where a favorite item or a few items of the deceased is kept.

• Creating a memory garden where a plant is planted and looked after.

• Creating a memory workbook where the person can choose to include things like photos of the person, a list of favorite things such as foods and places etc.

• Helping the person create a painting or a collage or another piece of artwork that represents the deceased person.

• Assisting the person to write an unsent letter to the deceased if they felt they had things to say that they couldn’t say at the time, or did not have an opportunity to say.

• Helping the person make a book of sympathy cards that were received.
• Helping the person find a comfortable place to relax if they need some personal quiet time.
• Making a tape of the deceased person’s favorite songs.
• Helping the person to find a poem, saying or a song that helps them remember the deceased person, but that also brings a sense of comfort.
• Assisting the person to explore a new leisure activity.
• Assisting the person to develop and use a calendar as a way of planning and looking forward to coming events.
• Some of these ideas also appear in Luchterhand and Murphy (1998), which is a recommended resource in this area.

References

Other Resources

This publication is linked to the work of the Bridging Project. The Bridging Project is being undertaken by Scope in collaboration with the Centre for Developmental Disability Health Victoria, Monash University. The mission of the Bridging Project is to progress the knowledge and resource base to ensure that people with complex communication and mental health needs have access to quality services. The project has two complimentary streams, Building Evidence (increasing the evidence base in relation to individuals with complex communication and mental health needs through research and related activities) and Building Capacity (building the capacity of services to address the mental health needs and preferences of individuals with complex communication needs). The project is designed around the needs of people who are 18 years or older. More information regarding The Bridging Project can be found at the Scope Web Page, http://www.scopevic.org.au