

Autism & Grief Project

Fact Sheet



What is Grief?

Grief is a reaction to the loss of someone or something to which an individual has a bond or connection. Loss affects everyone, whether on the autism spectrum or not. Here are some key facts about grief.

- People have a range of reactions to loss; the experience of grief is highly individual.
- Grief can affect people cognitively, emotionally, physically, mentally, and spiritually.
- Some grief responses are more socially sanctioned and/or more noticeable than others; all responses should be validated.
- Grief does not follow a timetable or “stages”; some people may seem to process their grief quickly, while others take longer, and grief can be triggered months or years after a loss.
- Grief can begin before a loss; for example, a long illness may involve grieving multiple losses as abilities and roles change.
- Adults grieve all kinds of losses, including non-death losses that may ultimately impact a person’s well-being. The end of a relationship through divorce or other circumstance is an example of a non-death loss.
- Loss may also include the inability to participate in an activity, such as a job or enjoyable pastime. If an object of importance goes missing, feelings of grief can also surround the absence of that object.
- Individuals have different styles of grieving. Some are highly emotive; others focus on a project or activity as a way of expressing grief. Others fall somewhere in the middle. Grieving styles can differ among families or friends.
- Circumstances surrounding a death can impact the grief experience. A sudden, unexpected death can shatter a person’s previous sense of safety. Major life changes resulting from a death can have the same effect.
- No manner of grieving is “wrong” unless the griever is harmful to themselves or others.
- People often cope with grief in ways they have coped with previous crises in their lives. Some grievers may benefit from support groups or peer support. Others may find comfort in reading books or websites about grief. Others may cope on their own without formal support.
- Most people who are grieving return to levels of previous functioning around six months after a loss (although there is no fixed timeline). While there is no body of research on grief in the autistic population, numerous interviews conducted for this website indicate that some adults with autism may have limited grief reactions until months or years after the loss. Again, there is no timeline for grief. In addition,

autistic people may exhibit emotions and reactions that are simply not recognized as grief by non-autistic people. If concerns arise about a griever who does not seem to be coping adequately, and if grief seems to persist, referral to a professional grief counselor may be appropriate. See section on finding a counselor.

Contemporary Grief Theories

While current research has not included adults with autism, understanding current grief theory is helpful to any professional working with any grieving individual. Perhaps most importantly, professionals should absolve themselves of the notion that grief occurs in stages. This theory was developed by Elisabeth Kübler-Ross, a pioneer in the field of death and dying in the 1960s. She based her work on observations of people with a terminal illness. Stage theory has long been debunked as applicable to those who are grieving but persists among both professionals and laypeople. Stage theory can be unhelpful and even harmful to grievers, as they may come to think that they aren't grieving "correctly" if their grief process does not follow a linear path—which no one's grief process does.

Significant contemporary grief theories, all of which are evidence-based and can provide support and comfort to those who are experiencing grief, include the following. While these theories are based on neurotypical populations, they can illustrate some of the issues that may complicate grief in persons on the spectrum.

Worden's Tasks of Mourning Model

Dr. J. William Worden's Task Model of grief (1982) describes the grief journey as a series of tasks that must be accomplished during the mourning process. Tasks are not ordered, prescriptive, or linear; they can be revisited and reworked throughout the grieving process.

- **Accept the reality of the loss** – Bereaved persons need to acknowledge the reality of the loss of the person.
- **Experience pain of grief** – Most people understand that losing a loved one is often painful. Part of the grief journey includes the experience of this pain and, in fact, all the emotions of grief. Feelings like anger, guilt, and loneliness are all normal reactions to loss. Grievers may need to "dose" these emotions or need to back away from experiencing pain from time to time and reapproach it as they are able to handle it effectively.
- **Adjust to life without the deceased** – Life without the person who died is irrevocably changed, and these changes require grievers to adjust to a new life without them. There are three types of adjustments a griever might face:
 - a. *External adjustments (roles and functioning)* This might require learning new concrete skills such as mowing the lawn or balancing a checkbook. It may also include seemingly smaller adjustments, like eating dinner or watching television without the person.

- b. *Internal adjustments (sense of self, self-efficacy)* The bereaved person may ask questions such as “who am I now without the person who died?”
- c. *Spiritual adjustments (Shattered assumptions, beliefs, values)* Losses often shatter the assumptive world of a griever – the idea that the world is essentially safe. Spiritual and religious beliefs may also be affected, either by being strengthened or by raising questions or internal conflict.
- **Finding an enduring connection while embarking on a new life** – Bereaved people maintain continuing bonds with their loved ones after the death (Klass et al., 1996). This may include thinking about the person, participating in rituals of remembrance, or even wearing a favorite sweater or article of clothing. These tangible reminders of continuing bonds help the grieving person embark on a new life without the person with less fear that they will not stay connected in some way.

It also is important to remember that continuing bonds are not helpful for everyone, and in some cases can be destructive or damaging. For example, if the relationship with the deceased was strained or unhealthy (e.g. enmeshed, co-dependent, or, at the extreme, abusive), maintaining bonds may continue unhealthy relationship patterns of attachment. In other cases, the amount of effort the individual invests into continuing bonds may be all-consuming and lead to maladaptive behaviors that prevent the individual from activities of daily living, or from establishing healthy attachments to others in their life.

Task Theory and Autism

As noted earlier, in a person with autism, grief tasks can be impacted by their autism itself. Feeling the emotional impact of the loss may actually be more intense than in the neurotypical population, but to a professional without autism experience, that reality may not be outwardly clear due to differences in communication styles and behaviors. This may be especially true for those who use communication devices or who don't use spoken language. Furthermore, the autistic's adjustment to life without the deceased may include life-altering changes if the death was that of their caregiver. A caregiver's death often results in a domino effect beyond the death itself—loss of the relationship, the need to move to a new place, loss of familiar routines and stability. Routines and structure are often very important for autistic individuals and disruptions can be distressing. This sort of death might literally re-order their entire lives.

As previously stated, grief is individual and unique. Therefore, these tasks are mediated by the lived experience of each person experiencing grief. Mediating factors include:

- Kinship – relationship to the deceased (spouse, child, parent)
- Attachment – nature of the relationship (strength of attachment, unfinished business, or conflicted relationships)
- Death factors – cause of death, whether it was sudden or expected, preventable or violent, all play a role in the grieving process of a loved one. A

death that results from a long illness can still be experienced as a sudden death.

- Personal history – experience with previous losses
- Personality variables – coping styles, attachment style, cognitive ability, mental health, self-esteem
- Social factors – level and quality of support available to the grieving person, (family resources, religious resources, community resources, etc.)
- Concurrent stresses – secondary losses, other losses surrounding the death

Dual Process Model

Researchers Dr. Henk Stroebe and Dr. Margaret Schut developed the Dual Process Model of Coping with Bereavement (1999). Their theory proposes that bereaved individuals oscillate between loss-oriented and restoration-oriented responses to cope with loss.

Loss-oriented responses include:

- Grief work
- Intrusion of grief
- Letting go – continuing/relocating bonds
- Denial/avoidance of restoration changes

Restoration-oriented responses include:

- Attending to life changes
- Doing new things
- Distraction from grief
- Denial/avoidance of grief
- New roles/identities/relationships

The oscillation between these orientations allows the grieving individual to experience the emotions and other impacts of grief while also continuing through daily life. Yet, autistic individuals can become highly focused on one thought or activity, which could inhibit their ability to oscillate. Oscillation should be encouraged to prevent emotional overload. Overload of the loss-oriented responses may lead to prolonged or complicated grief. In restoration-oriented overload there may be inhibited grief reactions or stress disorders. Since emotional overload is a frequent attribute of autism, these reactions may be compounded in autistic adults. Professionals should allow and encourage the bereaved individual to move between these reactions, and to use this model to ensure them that this process is very common for grievers.

Conducting a Loss Inventory

Grief assessment often includes conducting a personal history of previous losses experienced by an individual. This “inventory” of prior events involving loss can help to identify ways that former losses are influencing a person’s grief. In addition, an inventory may reveal an individual’s coping behaviors, styles, and adaptations to prior loss, which can help guide the most useful responses and interventions.

Given the wide range of the autism spectrum, professionals should employ techniques that enable effective assessment (visit the section Autism & Grief for more information). With nonverbal clients, for example, clients can be asked to respond to pictures or other visual prompts. If there is no other option to communicate directly with the adult with autism, clinicians may need to seek assistance from family members or others in the person’s network.

A loss inventory should gather the following type of information:

- Were there prior death losses and when did they occur?
- How did the individual respond to those prior losses?
- Are these previous losses affecting response to the current loss?
- How are secondary losses that resulted from the previous loss affecting the individual? For example, did the prior death lead to any changes in the individual’s life, such as loss of other relationships, changes in daily routine, loss of treasured activities or objects, or a change in living situation?
- Non-death losses can include divorce, relocation, loss of relationships with parents, siblings, caregivers, partner, spouse, friends, or housemates, or loss of an object or cherished activity.
- Pet/animal companion loss – including not only death but separation.

When taking this inventory:

- Account for inconsistent responses. Attempt to understand underlying factors if the individual’s way of coping with a current loss seems different from the ways they have coped in the past.
- Assess for trauma. Loss that is traumatic often influences grief responses. Has the person experienced any loss or change, or has the person endured bullying, ostracization, or rejection that now makes the individual lose faith in other persons, beliefs, or makes the person feel more vulnerable?

Helpful Evidence-Based Terms That Can Be Used to Support and Understand Grief

Some terms which might be helpful when supporting grievers, especially autistics, are below. Please note that this list is not exhaustive. Also, it is important to recognize that these are not diagnostic criteria, and most often individuals will process their grief without professional intervention.

- **Anticipatory grief:** First described by psychologist Eric Lindeman, anticipatory grief is the grief an individual may experience when they are aware of the impending death of a loved one. Rando reminds us that the term is useful but somewhat of a misnomer. Persons with life threatening illness are not only mourning an impending death, but also the losses experienced during the course of an illness, such as the loss of functions, roles and relationships, because these losses are both experienced and anticipated. Research indicates that anticipatory grief does not lessen or shorten the grief a survivor may experience after a loved one dies. Anticipatory grief can be experienced by patients, their intimate network of family and friends, as well as professional caregivers.
- **Disenfranchised grief:** Dr. Kenneth Doka developed this term, which describes the experience of a person whose grief is not respected or supported by their community or within the larger society. It might also be used to describe the grief experience of a person who has been marginalized by society, thus receiving less support or respect in their grief. Disenfranchised grief can occur for people with autism, even unintentionally. Some examples include if the person is kept from participating in the funeral or other rituals, or if their expression of grief is not socially sanctioned or appears different from others in the family.
- **Meaning making:** Much like Worden's Fourth Task of Mourning, many researchers (see Niemeyer) have posited that one part of processing or healing from grief is through finding ways to make meaning of the loss. Many people turn to their faith and/or other forms of spirituality but it can take many forms, such as advocating for others (i.e., Mothers Against Drunk Driving) or creating a memorial (such as a monument, or a scholarship), but it can also be more personal (such as dedicating a life choice or experience to the deceased).
- **Chronic or prolonged grief:** Chronic or prolonged grief is a term used to describe grief which seems to remain at the same intensity level as the initial acute grief experience. Although experts disagree about how or when to define grief as being prolonged or chronic, most will agree that it is when the grief doesn't start to ameliorate over time. For many, grief will come in what feels like waves. Initially, a grieving person may focus more on the loss or deceased one, but over time, will start to spend more time on regular or pre-loss daily activities. This does not mean that the griever may not re-experience strong grief reactions (such as the oscillation described by Stroebe and Schut), but that those tend to diminish after time.
- **Complicated grief:** Much like chronic or prolonged grief, there is significant disagreement about what constitutes grief that is complex or complicated. Ultimately, it is usually considered from a functional perspective. When the grief experience is so extreme that the person is unable to function; to build or maintain existing or new emotional attachments at a level that they did prior to the loss; and/or is experiencing symptoms indicative of posttraumatic stress disorder, anxiety, or depression, it could be indicative of complex or complicated grief, and may require professional

intervention to help the person reestablish healthy adaptive behaviors and relationships with others.

- **Intuitive or Instrumental grief:** These terms come from the work of Doka and Martin and are often used when describing someone's grieving "style." Those who use more intuitive coping mechanisms may find more comfort in expressing their grief through language, or sharing of emotions with others, whereas those who use more instrumental expressions of grief may be more inclined to be action-oriented and may find more comfort from task-oriented coping mechanisms. Most individuals use a combination of strategies or approaches, but many will demonstrate a preference for emotion-oriented or task-oriented coping.

References:

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