



WHAT IS GRIEF?

Grief is a reaction to the loss of someone or something we have a bond with. It affects us all, whether we're on the autism spectrum or not. The loss could be the death of a family member, friend, coworker, teacher, or a beloved pet. But we can also experience grief after the loss of a job or relationship, or after a divorce or other change in a family or living situation. It can also occur when we're facing our own or a loved one's serious illness or death.

Here are 10 important things to know about grief and 5 ways it may further impact a person with autism:

1. Grief is as individual as a fingerprint. No two people's grief is the same, and even two loss events in our lives might result in different grief experiences.
2. There are no universal "stages" or steps that we go through grief. Each of us has our own personal grief response and grieving style, and how we grieve is not a measure of how much we loved the person who died. [link to grieving styles]
3. Grief doesn't follow a timetable. It can be thought of more as a rollercoaster than a timeline because the experience is full of ups and downs. There are times that things seem to be better and times when things seem worse. And like a rollercoaster, the beginning of the ride isn't always the most intense part of the experience.
4. Grief can occur before a death. This grief is known as *anticipatory grief* or *anticipatory mourning*. It's not uncommon for our losses to stack up during the course of a serious illness as we anticipate our own death or that of our loved one. It's also possible for us to experience grief reactions before we lose something important in our lives, such as an upcoming change in living situation or the loss of a job. [link to anticipatory grief]
5. Grief may cause physical and cognitive symptoms. Some of us may experience grief in our bodies, as we get stomachaches, headaches, or other physical pains or ailments. There's evidence that grief can affect our immune response, too. Grieving may affect our ability to focus on school, work or other tasks we don't usually have trouble focusing on.

6. Grief may impact our spirituality, either by raising challenging questions and/or by strengthening our faith and beliefs. These responses are to be expected. [link to spirituality]
7. New loss may bring up old grief. New losses can create reminders of previous losses, especially if we have unresolved feelings related to our prior losses.
8. Loss can have a domino effect. A person's death can bring about other losses for us, such as a change in where we've called home or our connection to friends or caregivers who had been a part of the deceased person's life.
9. Grief does not mean the end of our connection to the person who died. The pain of grief typically lessens over time, and sometimes we may be afraid to let go of intense grief for fear of losing our connection to the deceased. But our bond will continue through memories of our loved one and the activities, objects, and places we shared. We may recognize our own traits and skills that are similar to the deceased's and reaffirm our ongoing connection.
10. Conflicted and highly dependent relationships in life can lead to complications with grief. Complicated grief can negatively impact our daily life in many ways and on many levels, and it can be exacerbated by multiple diagnoses including anxiety and depression. [link to complicated grief]

For individuals with autism, grief and loss may:

1. Result in no outward change in behavior following the loss, which should not be mistaken for lack of understanding or sadness.
2. Be routinely disenfranchised, meaning that they are not properly validated, recognized, or respected by those around them. [link to disenfranchised grief]
3. Cause regression, anxiety, and stress resulting in a feeling of being disconnected from their own emotions.
4. Cause increased stimming and other soothing behaviors; food refusal; sensory overload; loss of verbal communication clarity; increased meltdowns, and a general agitation.
5. Cause anxiety related to how they should appropriately react to the death or the rituals surrounding the death; including how to communicate about the death and/or feelings, how dress or act in a setting such as a memorial service or funeral, and how their life may change as a result of the death. [link to funeral section]

6. It is not unusual that individuals on the spectrum may experience and express grief in terms of physical complaints and manifestations such as nausea, headaches, body aches, etc.

Grieving Styles

We all grieve in different ways. Our individual responses to loss are often referred to as “grieving styles.” These styles may be influenced by, but are not determined by, our gender, ethnicity, culture, and/or their autistic strengths and challenges are. Oftentimes, the grieving styles of spouses, partners, parents, and other members of the same family are very different.

The differences in the way we each grieve and cope might seem to be a measure of the amount of our grief, but they aren’t. The way we grieve doesn’t indicate the amount of love we each have for the person who has died, it’s just our personal way of responding to the death.

There are four common styles of grievers:

- “Heart” Grievers - For those of us whose grief is a highly emotional experience, we’re known as “intuitive” grievers. We may experience strong, and even contradictory, emotions such as anger, guilt, loneliness, sadness, or yearning for the person who died. These expressions of grief might mirror our inner feelings through crying, rage, or withdrawal.
- “Head” Grievers – Those of us who grieve with less intense outward emotions are known as “instrumental” grievers. We might express grief in a more cognitive way, by thinking about the person often and taking action in response to the death. Some examples could be making a photo album, putting together a music playlist, or engaging in physical exercise.
- “Heart + Head” Grievers - Many of us experience grief in some combination of the styles above, and we’re known as “blended” grievers.
- Heart vs. Head Grievers – Some grievers may experience grief as a highly emotional experience but repress these feelings

These different ways or patterns of grief are just that—differences—not deficiencies. No pattern is better or worse. They’re simply expressions of the fact that each of us copes with loss in an individual way. Different grieving styles don’t need to be a source of

conflict. Complementary ways of coping within families or relationships can be a source of strength.

Each of us needs to and should be encouraged to express grief in ways that are comfortable. Understanding the different styles of grieving can be helpful in managing the potential conflicts that might arise between grievers of differing styles.

How can you help your loved one?

By remembering that we all:

- grieve because we love,
- grieve as we live,
- can't expect our loved ones to grieve the same way we do,
- grieve on their own time schedules,
- grieve differently and in the way that is right for us, and
- can validate and support our loved one regardless of how they grieve and cope.

Disenfranchised Grief

Sometimes our loss isn't openly acknowledged or publicly mourned by those around us, which may result in "disenfranchised grief." When we're disenfranchised, we are experiencing grief but our loss is either not recognized or acknowledged by others. When this happens it can cause us to feel that we're not being listened to, understood, or supported.

Some examples of significant losses that may not be acknowledged are:

- the death of a beloved animal companion,
- a non-death loss, such as loss of a job, a move, or a divorce,
- people leaving caregiving roles, which is especially common for adults living in facilities,
- the death of a publicly-known person or someone important to us, but our connection to that person is not understood or is unknown to those around us, or
- the death might be stigmatized in our culture or situation (death by suicide is one example).

Grief may also be disenfranchised when we, as the griever, are not recognized by others as someone who has the capacity to understand the loss or its implications.

Oftentimes the grief of children, the elderly, and those with dementia is disenfranchised. This reality is also true for people with autism as well as for people with intellectual and developmental disabilities.

When grief is disenfranchised, there are some complications that may occur:

- Grief may be intensified because it isn't recognized and the usual social support system that would normally help isn't there.
- Sometimes grievers are purposely kept away from serious illness, the person who is dying, or from the funeral or other rituals. While these decisions may be well-intentioned, and may also be necessary given the griever's ability to cope with the situation, this exclusion can lead to disenfranchisement.

How Can You Enfranchise Grief?

1. Be open to listening: "How are you feeling about Uncle John's illness?"
2. Be deliberate and clear with your words: "You loved Uncle John, and it's sad that he died."
3. Offer choices in how to proceed: "Do you want to look at pictures of Uncle John together, or do you need time alone?"
4. Provide reassurance: "I miss him too, but it's going to get easier."
5. Use the resources you already have. Draw on family, faith leaders, therapists, and other community supports to acknowledge grief and all feelings.

Building Resilience

Resiliency is a term that defines a sense of strength and personal control, which can be important to our ability to cope with grief. Some of us are highly resilient and able to cope well, even with significant loss. Resilient reactions are one of the many possible reactions to grief and remind us of the individualized nature of grief.

How can you help your loved one build resilience?

It is important to draw upon the individual's strengths when helping them to develop resilience.

- ***Create an effective support system*** — Identify a network of family, friends, and colleagues who might be helpful. Some people are great listeners while others are good at helping in other ways, such as providing meals or running

errands, and it's important to have different types of people within our support system. Grief is hard work and requires time off. Friends can offer respite, which can include helping us get away from grief by engaging in an enjoyable activity.

- **Find support in others who have had similar experiences** — Many of us find comfort in a grief support group or other type of support group, where we find validation and coping strategies.
- **Encourage patience with the process** — The journey with grief is uneven, with good days and bad days and we need to be patient with ourselves. Resilience can come through understanding that all of the ups and downs are part of our grief journey.
- **Review how grief has brought about positive change** — Recognize new insights and new skills that have emerged while coping with the loss.
- **Try expressive therapies** — Expressive therapies may be helpful for some of us. This can be especially true for adults with autism who have difficulty with verbally expressing their feelings. It is important to recognize that different people will respond to different kinds of therapies. For example, some may respond to music, while others will benefit from creative activities or physical movement. Drawing, painting, and other forms of artistic expression can be helpful, as well as dancing and walking in nature. Some may find comfort in looking at pictures of people in grief and/or pictures of experiences associated with death such as visiting a funeral home, loading a casket into hearse, people gathered at a cemetery, or other experiences related to your cultural traditions and practices.

Journeying with Grief

Coping with grief and loss is a challenge, but it can also bring new opportunities and achievements as we journey through grief. This is sometimes known as “posttraumatic growth.” Though grief can be difficult, we can grow stronger because of it.

How can you help your loved one “journey” through grief?

- Look at successful strategies from handling past crises and how they could be useful now. Some strategies may have included finding strength through personal spirituality, perspective, or faith.

Ask: “What or who helped you feel better last time?” or “What didn’t work?”

Try using pictures from that time period to jog memories. For example, look at a picture from the year that a close friend moved away, and talk about how that felt, and what helped in coping with those emotions.

- Focus on empowering language and positive memories. Sometimes what seems like a small choice can bring a great sense of control and comfort. Creating a photo collage or finding a special memento of the person who has died can help as a reminder that the connection and memories will continue. Having a physical reminder of the person who died may be especially important for a person with autism. The concept of death is intangible and abstract, and thus hard to understand and grab hold of. Having a tangible item to hold may offer a connection to the deceased that is easier to grasp cognitively.
- Remember that while life after a death or a loss will be different, there will be moments of joy and happiness. When supporting yourself or an adult with autism, keep sight of the future. Perhaps setting small goals for where you or they wish to be next week, next month, or next year, and considering small daily changes can help achieve those goals.

Responding to People Who Say Unhelpful Things

Death remains a difficult subject for many people, and it's quite common for people to say the wrong thing as they try to provide solace and comfort. Though well-intentioned, these statements can be hurtful.

- *Platitudes like “at least they’re not suffering anymore” are unlikely to ease the pain of loss.*
- *“God needed another angel” also diminishes the pain of the griever.*
- *Statements related to the adult with autism’s ability to understand or grieve can be especially hurtful. “At least they don’t understand” disenfranchises their grief.*

When you encounter this “unhelpful help”, try to remember that the comments aren’t made maliciously. Establish clear boundaries, and don’t be afraid to stand up for your needs.

- *“I know you’re trying to help, but right now I don’t need that.”*
- *“What we actually need is...”*
- *“He’s Uncle Mike’s favorite nephew. Of course he will be at the funeral, just like everyone else.”*

Grief While Caregiving

Grief when we're caregiving can be especially tricky. We are simultaneously experiencing our own loss, while also supporting our loved one with autism. We may experience feelings of being overwhelmed or experience caregiver burnout. It also might feel distressing when our loved one with autism doesn't grieve in the same way we do. All of these feelings are valid, and self-care is especially important in times like this. You might use meditation, prayer, journaling, or other coping mechanisms that have been helpful to you in the past. Don't feel guilty about reaching out for help if it's needed. We need to care for ourselves as we care for others and utilize available resources as often as necessary.

View our self-care tips at [www.autismandgrief.org/\[page\]](http://www.autismandgrief.org/[page]).