



What is Grief?

Grief is a reaction humans have to the loss of someone or something to which we have a bond. It affects us all. These are common causes of grief for all of us:

- the death of a family member, friend, neighbor, coworker, teacher, or beloved pet;
- the loss of a job or relationship, or a major life change such as a divorce or move;
- community or world events, such as the COVID-19 pandemic;
- the death of someone we never knew personally, such as a political leader or celebrity; or
- our own or a loved one's serious illness or impending death.

Autistic people can also grieve the loss of objects to which they were emotionally attached, special hobbies or passions, or a safe space they count on for security.

Grief and its effect on the neurotypical population has been extensively researched; there are countless studies to help us understand its impact. In contrast, the study of the effect of grief on adults on the autism spectrum is just emerging.

5 Important Universal Facts About Grief

1. Grief is as individual as a fingerprint.

We each have our own personal grief response and coping style, and the grief of two different loss events might result in different grief reactions. How we grieve is not a measure or indication of how much we love the person who died, it's simply our personal response to the loss.

2. Grief doesn't follow a timetable.

There are no prescribed stages that chronologically lead us through grief. The grieving process can be thought of as more of a rollercoaster than a timeline because the experience is full of ups and downs. A new loss might bring up grief from a prior loss, and the reaction to the new grief might be very different than the reaction to the prior loss.



3. Grief can cause physical, emotional, cognitive, and spiritual challenges.

Grief can cause physical ailments such as stomachaches, headaches, and other aches and pains, and there is evidence that it can affect our immune response as well. It can affect our ability to focus on school, work, or other tasks. Grief can also impact our spirituality by challenging our personal faith and/or by strengthening our beliefs.

4. Grief can occur before a death.

As we anticipate someone's death and the accompanying losses, we can experience what is known as anticipatory grief. We can also experience this grief reaction before we lose something important, such as a change in living situation or the loss of a job.

5. Grief can be complicated.

Conflicted and highly dependent relationships in life can lead to complications with grief that can negatively impact daily life in many ways and on many levels. It can also be exacerbated by multiple emotional or psychological responses including anxiety and depression.

Autism and Grief

For adults on the spectrum, grief may cause emotional, behavioral, physical, and cognitive responses that are similar to stress responses in the neurotypical population.

In addition, an autistic individual's response can be affected by their understanding of the loss and/or ability to communicate. For some, coping with the abstract nature of death can be difficult. Many individuals with autism are concrete thinkers, so they might easily grasp that a person is gone but may struggle with identifying their feelings about the person's absence or how their routine may be impacted.

For autistic individuals, grief may result in:

- **Behavioral changes** — Responses may be an increase in self-stimulatory and other soothing behavior, food refusal, sensory overload, loss of verbal communication clarity, increased emotional outbursts, increased argumentativeness or oppositional speech, sustained crying or no crying, or a general agitation.
- **No outward change** — The lack of a behavior change should not be mistaken as a lack understanding or sadness. Presenting as unexpectedly calm may be an indication the autistic person is overwhelmed.



- **Developmental regression and appearing stressed** — Such responses can be the result of disconnection from their own emotions. They could also result from an individual not feeling what they think others expect them to feel.
- **Physical changes** — Physical responses such as nausea, headaches, body aches, or menstrual or gastrointestinal irregularities can be common in grieving autistics.
- **Anxiety** — This may be related to concerns about how to appropriately react to the death or the rituals surrounding it, including communicating about the death and/or their feelings about it; how to dress or act during a service or funeral; how to respond to strong emotions from others; or how their life may change because of the death.

Acknowledging an Autistic Adult's Grief

We all hope our grief will be acknowledged by those around us. Unfortunately for many autistic adults, loss is not always compassionately supported or even recognized. This lack of recognition can result in what grief experts call disenfranchised grief, leaving the griever, autistic or not, feeling that their loss is neither valued nor supported.

To ensure your loved one with autism feels respected and validated, we offer these suggestions, which should be tailored to the individual's needs:

- **Be open to listening.** Identifying feelings might be difficult, so it may be helpful to ask what they *think* about the circumstances rather than what they *feel*. “What do you think about your friend's death?”
- **Be deliberate and clear with your words.** “You were close with your friend, and it's sad that she died.”
- **Offer choices regarding how to cope.** “Do you want to look at pictures of you and your friend, or do you need time alone?”
- **Include them.** Involve them as much, and as often, as they would like in both the planning for and attendance at the events and rituals that surround the death.
- **Use the resources you already have.** Draw on family, faith leaders, therapists, and other community members who the autistic person feels are safe and supportive to help acknowledge their grief.



- **Provide reassurance.** “I miss her too, but these thoughts and feelings get easier over time.”
- **Notice changes in behavior.** Grief is often expressed through behavior changes, such as:
 - showing no affect or extreme affect,
 - stimming or increased vocalizing/self-talk,
 - not speaking, even though previously verbal, or
 - disrupted routines, such as those involving eating, sleeping, or hygiene.
- **Do not be critical of their expression of grief.** Grief is individual and may be expressed in many ways. Expressions of grief should be accepted, even if they’re not typical. Respond to behaviors in ways that you have found helpful with other stressful events in the past and/or see out others (e.g., family members, therapists, etc.) who have provided helpful support in the past.

When Grief is Unacknowledged

There are many reasons people may consciously or unconsciously fail to acknowledge to the grief of an autistic adult. It may be because they:

- are caught up with their own grief, and are unable to address or understand the needs of a grieving autistic adult;
- believe the person with autism is not grieving if their grief is not displayed in conventional ways and therefore believe support is unnecessary; or
- hope to shelter the individual from the pain of grief by acting like the loss is unimportant.

An autistic adult’s grief might go unrecognized by intentional or uninformed actions or inactions. For example:

- the autistic’s concern, anxiety, or anticipatory grief during a loved one’s terminal illness may be ignored;
- they may be prevented from saying goodbye or visiting at the end of a loved one’s life;
- the death may be concealed, denied, and/or not discussed;
- incorrect assumptions might be made about their ability to understand;



- they might be intentionally excluded from funeral or memorial services;
- their behaviors may be viewed as “difficult” instead of being recognized as possible grief reactions; or
- they may be misunderstood and/or judged for not reacting to loss as others do.

Grief can also be unacknowledged when a loss does not involve the death of someone in their intimate network. This is a common experience for all of us, but those with autism may be especially vulnerable. Significant losses that may go unacknowledged are the deaths of:

- a beloved pet or animal companion;
- a caregiver, whether living with family or in a congregate setting;
- someone who was important in their life, but the connection was unknown to family (especially likely when the individual lives away from family);
- a celebrity or public figure, when the person’s connection to them is not well understood by others;
- someone who died by suicide, addiction, or another type of death that is often stigmatized; or
- a non-death loss, such as the loss of a job, important activity, or object they were emotionally attached to; a move or divorce; or the replacement of a professional support person.