

Autism & Grief Project

What is Grief Fact Sheet



What is Grief?

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

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 living situation;
 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.
 For autistic people, they can also grieve the loss of objects they were emotionally attached to, special interests or passions, or a safe space they have counted on for security.

Grief and its effect on the neurotypical population has been extensively researched and 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.

6 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 experiences. 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. Visit the We Grieve Differently section to learn about the differences in how we grieve.

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 old grief and result in a different grief reaction.

3. Grief doesn't keep us from remembering a loved one

The pain of grief typically lessens over time. For many, however, the thought of letting go of intense grief can sometimes create the fear that they will forget the person who

died. However, remembering a loved one continues through memories and the activities, objects, places, and even the traits and skills that were once shared.

4. Grief can cause physical, mental, 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 raising challenging questions to our faith and beliefs and/or by strengthening those beliefs. Visit the Role of Religion & Spirituality section to learn more.

5. 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. Visit the Coping with Serious Illness section to learn about anticipatory grief. More information about grief reactions to non-death losses can be found in the Non-Death Loss section.

6. 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.

Grief and Autism

For adults on the spectrum, in addition to the list above, grief may cause emotional, behavioral, physical, and cognitive responses that are similar to stress responses seen in the neurotypical population. An autistic individual's response can also be affected by their understanding and ability to communicate. For some, coping with the abstract nature of death can be difficult. Many individuals with autism are very concrete thinkers, so they might easily grasp that a person is gone but may struggle more with identifying their feelings about the person's absence or how their routine may be impacted.

Grief for autistic individuals may result in:

- Behavioral changes — These 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 of understanding or sadness. Presenting as calm can be an indication the autistic person is completely overwhelmed and possibly even in crisis.
- Regression and stress — These responses can be the result of being disconnected from their own emotions. It could also be the result of not feeling what they think others are expecting them to feel.
- Physical changes — Physical responses such as nausea, headaches, body aches, or menstrual or gastrointestinal irregularities can be common.
- Anxiety — This may be related to concerns about how to appropriately react to the death or the rituals surrounding it, such as communicating about the death and/or their feelings; 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 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 person'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 in 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 in the events and rituals that may surround the death.
- Use the resources you already have — Draw on family, faith leaders, therapists, and other community supports, 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 when 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 ask others (e.g., family members, therapists, etc.) who have done so.

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;
- think they can shelter the individual from the pain of grief by acting like the loss is unimportant;
- do not even realize they are doing it.

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

- their concern, anxiety, or anticipatory grief during a loved one's terminal illness may be ignored;
- they may be kept from saying goodbye or visiting at the end of a loved one's life;
- the death may be concealed and/or not discussed;
- incorrect assumptions might be made about their level of understanding or ability to understand;
- they might be intentionally excluded from funeral or memorial services;
- their behaviors may be viewed as "difficult" instead being recognized as possible grief reactions;
- they may be misunderstood and judged for not reacting to loss like others.

Grief can also be unacknowledged with losses that do not involve the death of someone in an 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 death of:

- a beloved pet or animal companion;
- a caregiver, whether living with family or living in congregate care settings;

- someone important in their life, but the connection was unknown (especially true when the individual lives away from family);
- a celebrity or public figure, when their connection to the person is not understood by others;
- someone who died by suicide, addiction, or another type of death that is often stigmatized by a culture or situation; 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 professional support person.