



Autism & Grief

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Learning Objectives

Describe the autism spectrum and the highly individual nature of both autism and grief.

Discuss the many ways that an adult with Autism Spectrum Disorder (ASD) may visibly or verbally react, or not, to loss.

Define Doka's theory of disenfranchised grief and indicate how disenfranchisement can complicate the grieving process, particularly for adults with autism.

Identify three ways to enfranchise adults with autism in the grieving process.



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Learning Objectives

Discuss the ways that persons with ASD may experience their own life-threatening illness or that of a loved one.

Identify several support techniques when addressing serious illness and loss, taking into consideration effective communication and other person-centered techniques.

Discuss strategies for partnering with clergy and others who may be involved in grief supports.

Identify three ways in which, in the context of your work or your community, you can help support autistic individuals and their families in their ongoing grief beyond the immediate period of the funeral and burial.



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A Note about Language

The Autism and Grief Project recognizes that the use of identity-first and person-first language is a personal choice and respects these views by using both styles throughout this program and the AutismandGrief.org website.



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Behavior Changes in Grief

Grief for autistics **may** result in:

- Changes in appetite
- Changes in sleep patterns
- Not taking an interest in things once enjoyed
- No outward change in behavior or a lack of affect — this should not be mistaken for a lack of understanding or sadness
- Increased self-soothing behaviors; food refusal; sensory overload; loss of clarity in verbal communication, increased argumentativeness, or oppositional speech; increased emotional outbursts, meltdowns, or sustained crying; no crying; or general agitation.



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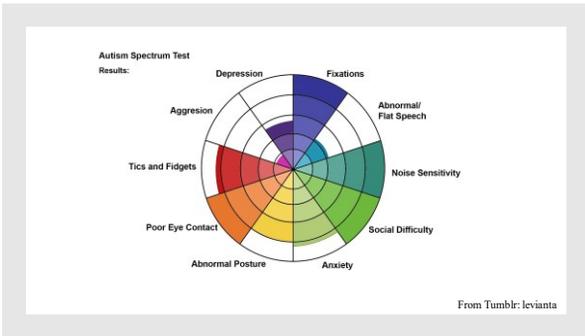
Characteristics of Autism

Autism presents differently in each person; however, there are common characteristics observed in the autistic population:

- finding it hard to understand what others are thinking or feeling;
- becoming very anxious about social situations;
- finding it hard to identify or communicate feelings;
- interpreting language very literally—for example, not understanding sarcasm or idioms such as "break a leg;"
- following the same routine every day and becoming anxious if it changes;
- not understanding social "rules," such as that one should not talk over people;
- avoiding eye contact;
- noticing small details, patterns, smells, or sounds that others do not;
- pursuing a keen interest in certain subjects or activities;



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Autism

- Autism is a developmental disorder that affects behavior, language, and cognition
- Autism is not limited to one presentation, symptom, or gene and is referred to as a “spectrum” due to its high degree of variability
- 40 – 50% of autistics have some degree of intellectual disability (Charman, 2011) (50 to 60% do not)
- 25 – 30% of autistics are non-speaking or minimally verbal (Tager-Flusberg, 2013)
- One in 45 U.S. adults is autistic (CDC, May 2020)



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What is Grief?

- Grief is a reaction to loss
- Grief is highly individual
- Grief can affect people:
 - cognitively
 - emotionally
 - physically
 - spiritually
- The experience of grief is not limited to the neurotypical population



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No Timetable for Grief

- Over time the pain of grief lessens
- The loss is usually incorporated into life going forward
- Most people can resume previous level of activities and functioning following a loss



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Disenfranchised Grief

Grief that is not openly acknowledged, socially supported, or publicly mourned.
(Doka, 1989)



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Communicating About a Death

- Use clear, concrete language
- Avoid euphemisms
- Be open and honest with the facts
- Be willing to repeat information as needed
- Narrate the experience – give words to emotions



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Types of Non-Death Loss

- Divorce
- Moving to a new house, apartment or living situation
- Job loss
- Change in support person or advocate
- Loss of a relationship, even negative relationships
- Diagnosis of a serious illness
- Loss of a pet or animal companion
- Loss of a special object
- Loss of hobby or passion



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Continuing Bonds

Continuing bonds is the concept of keeping a connection to the deceased long after the death.

This is done through:

- Memories
- Spirituality
- Shared Experiences



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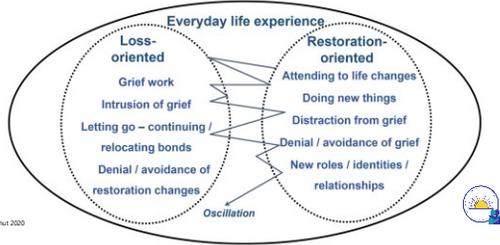
Worden's Tasks of Mourning

- **Accept the reality of the loss.** Bereaved persons need to acknowledge the reality of the loss of the deceased.
- **Experience the pain of grief.** Part of the grief journey involves experiencing all the emotions of grief. Feelings like anger, guilt, and loneliness are all normal reactions to loss.
- **Adjust to life without the deceased.** Life without the person who died is irrevocably changed, and these changes require a griever to adjust to a new life without them.
- **Find an enduring connection while embarking on a new life.** Bereaved people maintain continuing bonds with their loved ones after a death.



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Stroebe and Schut's Dual Process Model



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Neimeyer's Meaning Making

One aspect of processing or healing from grief is through finding ways to make meaning of the loss.

Meaning making can take many forms, such as:

- turning to faith or spirituality
- advocating for others (i.e., Mothers Against Drunk Driving)
- creating a memorial, such as a monument or a scholarship
- dedicating a life choice or experience to the deceased



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Alternatives to Talk Therapy

- Somatic work – movement or breathing
- Art therapy
- Music therapy
- Animal-assisted therapy
- Drama therapy



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Section Recap

Autism spectrum disorder is widely variable and includes people with high support needs and low support needs.
People with autism have challenges involving social skills, verbal and non-verbal communication, and repetitive or rigid behavior. Autism spectrum disorder now includes those formerly diagnosed with Asperger Syndrome.
Adults with autism may not verbally or visibly express their grief in accordance with social expectations. Such differences do not indicate the absence of grief.
Modern grief theory dispenses with the notion that grief occurs in stages and instead draws on the highly individual pathways of a person's grief experience.
Because autistic grievers may present differently than neurotypical grievers, their grief may be disenfranchised, meaning it is not openly acknowledged, socially accepted or publicly mourned.
Adults with autism may be enfranchised by recognizing and supporting signs of grief, such as physical aches and pains, lack of interest in previous activities that were important, or changes in appetite or sleep.
Clergy, health and human service professionals can provide support in many ways beyond the immediate period of loss, including being present for the person who is grieving, recognizing that grief reactions may occur many months or even years after a loss, and ensuring that others in their support network are aware of the loss.



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Suggestions for Healthcare Professionals

- Schedules are important – stick to arrival times, length of visits
- Communicate what to expect
 - What are the roles of each team member?
 - What are the social rules for the interaction?
- Give opportunity for breaks – allow space to take time alone
- Prepare for a different environment
 - What will the hospital look like?
 - Will there be unfamiliar sounds or smells?



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Section Recap

When discussing a death with an autistic adult, it is important to avoid euphemisms such as “in a better place” and provide factual information.
Like neurotypical adults, adults with ASD may experience anticipatory grief if they or a loved-one has a life-threatening illness. Anticipatory grievers mourn the losses often associated with serious illness as well as their or a loved one's expected death.
Hospices and other healthcare providers need to be aware of autistic family members and tailor their care to be family- and person-centered.



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Tips for Funerals

- Plan ahead
- Allow for breaks or time away from large groups
- Have a plan for leaving early if things are overwhelming
- Give opportunities for participation in rituals
- Lower the social stakes
- Appoint a companion or supportive person who may be further removed from the event



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Suggestions for Clergy

- Ask questions – “What are your needs?”
- Respect all expressions of spirituality
- Remember boundaries and roles of comfort and support



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Social Stories and Other Resources Available at AutismandGrief.org



Social Story: Remembering My Loved One

I will always remember someone who is important to me after they die.



They will always be with me because of my memories.



Remembering someone who died may help me feel better.



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Section Recap

Funerals and other death rituals, such as memorial services, are important social constructs that may pose challenges for adults with autism.

Adults with autism should be offered the opportunity to have a role by either helping to plan, taking an active role in, or attending the funeral or other service. If not possible, substitute options may include virtual attendance or an alternative ritual.

Some adults with autism prefer unconventional services and rituals around death; these should be honored.

Viewing or visiting the place where the event will be held prior to the ceremony can help, as can a schedule, a support person who can serve as a companion, and a pre-planned exit strategy if necessary.



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Supporting the Ongoing Journey

- Remember grief has no timetable – expressions and reactions of grief can occur months or even years after the loss
- Recognize the secondary losses – losses that have occurred since or because of the initial loss may also bring profound grief reactions
- Be supportive of how life has changed – schedule disruptions and other changes need to be recognized, validated, and accommodated as much as possible



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