



## The Role of Clergy and Faith Leaders in Supporting Adults with Autism Through Grief and Loss

Kenneth J. Doka, PhD



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### Learning Objectives

Understand basic facts about Autism Spectrum Disorder (ASD).

Discuss current grief principles.

Identify how autistic adults may react (or not react) to loss.

Identify how traditional religious beliefs and practices can present both benefits and barriers for adults with autism.



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## Learning Objectives

Discuss how spirituality may be expressed by adults with autism.

Delineate three techniques that clergy and others can utilize to assist autistics in navigating rituals.

Identify three possible ways to offer support to an adult with autism in faith communities and through their grief journey, beyond the immediate period of the funeral and burial.



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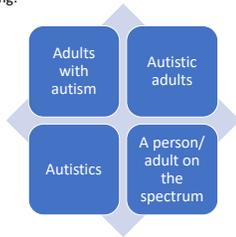
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## A note about language

The language used when talking about autism varies. Rather than take one approach, we will use the following:



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**“When you’ve met one person with autism,  
you’ve met one person with autism.”**

- Dr. Stephen Shore, former Board President  
Asperger/Autism Network (AANE)



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## What is Autism?

- Autism Spectrum Disorder (ASD) encompasses a broad range of behavioral, language, and cognitive differences
- 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)
- 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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## DSM Changes

In the previous version of the Diagnostic and Statistical Manual of Mental Disorders (DSM), there were four types of autism within the ASD category.

- Autistic disorder
- Asperger syndrome
- Childhood disintegrative disorder
- Pervasive developmental disorder not otherwise specified

Now: Under the DSM-5, someone with more severe autism symptoms and someone with less severe autism symptoms both have the same disorder: ASD

Some adults still choose to identify with an Asperger’s diagnosis  
<https://www.nichd.nih.gov/health/topics/autism/conditioninfo>



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## People on the autism spectrum also may have many strengths, including:

- Being able to learn things in detail and remember information for long periods of time
- Being strong visual and auditory learners
- Excelling in math, science, music, or art

[NIMH » Autism Spectrum Disorder \(nih.gov\)](https://www.nimh.nih.gov/health/topics/autism-spectrum-disorder/)



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## Characteristics of Autism

Autism is highly individualized, but autistic adults may:

- Have difficulty understanding what others are thinking or feeling
- Be very anxious in social situations
- Find it hard to make friends
- Seem blunt, rude, or not interested in others
- Find it hard to say how they feel
- Take things very literally
- Need the same routine every day and get anxious if it changes



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## Characteristics of Autism

Autism is highly individualized, but autistic adults may:

- Not understand social “rules” and norms
- Avoid eye contact
- Get too close to other people, or get very upset by physical touch
- Notice small details, patterns, smells, or sounds that others do not
- Have a very keen interest in certain subjects or activities
- Be logical thinkers, liking to plan things carefully before doing them



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## Learning Objective Recap

Understand basic facts about Autism Spectrum Disorder (ASD).



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## Learning Objective Recap

- Autism Spectrum Disorder or ASD is a developmental disorder that affects communication, behavior, language, and cognition.
- Autism spectrum is wide and includes those with Asperger syndrome.
- ASD is present in 1 in 45 US adults.
- Includes those with high support needs and low support needs.



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## Learning Objective Recap

- Person-first language (adult with autism) is preferred language for some; many with autism prefer to define themselves as autistics, while others prefer autistic adults or a person on the spectrum.
- Predictable routines, schedules and planning ahead may be highly important for those on the spectrum.
- Autistics may excel in many areas such as math, science, or art and may have the capacity to remember detailed information.



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## What is Grief?

**Grief is a reaction to the loss of someone or something to which an individual has a bond or connection.**

- Grief is a highly individualized experience
- 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



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## Grieving Styles

### Intuitive Grievers exhibit:

- Experiences strong affective reactions
- Expression mirrors inner feelings
- Adaptation involves expression and exploration of feelings

### Instrumental Grievers exhibit:

- Experience of grief is primarily cognitive
- Grief often is expressed cognitively or behaviorally
- Adaptation generally involves doing

Different styles of grieving may cause conflict or misunderstanding



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## Grief Reactions

### Grief for autistic adults *may* result in:

- No outward change in behavior or a lack of affect
- Regression, anxiety, and stress resulting in a feeling of being disconnected from their own emotions and/or not feeling what they think others expect them to feel
- Increased soothing behaviors; food refusal; sensory overload
- Loss of verbal communication clarity, increased argumentativeness, or oppositional speech
- Increased emotional outbursts, meltdowns, or sustained crying; no crying; or general agitation
- Rumination about a death or circumstances surrounding the death, causing the person to feel "stuck"



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## Grief Reactions

### Grief for autistic adults *may* result in:

- Increased echolalia, a term that describes "echoing" or repeating a word or phrase spoken by someone else
- Inability to express, describe, or identify feelings related to the loss, known as "alexithymia"
- Anxiety related to how they should appropriately react to the death or the rituals surrounding death
- Physical manifestations such as nausea, headaches, body aches, and intestinal or menstrual disruptions
- Sleep disruptions are common during grief
- Nighttime enuresis (bed-wetting) may also occur due to disrupted circadian rhythms and altered timing of sleep patterns



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## Learning Objective Recap

Discuss current key grief principles.



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## Learning Objective Recap

- The experience of grief is unique to each person.
- Grief is a lifelong journey that does not occur in stages.
- People maintain bonds with the deceased.
- Differences in grieving “styles” may cause discord in families.
- The initial intense pain often associated with death and other significant loss typically lessens over time.
- Grief can affect people on many levels, including, spiritually, cognitively, and physically.



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## Learning Objective Recap

Identify how autistic adults may react (or not react) to loss.



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## Learning Objective Recap

- There may be no outward change in behavior or a lack of affect for grieving autistics.
- Some adults with autism may exhibit increased soothing behaviors; food refusal; sensory overload.
- Grievers may have a loss of verbal communication clarity, increased argumentativeness or other oppositional behaviors.



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## Learning Objective Recap

- Some autistics may have an inability to express, describe, or identify feelings related to the loss, known as “alexithymia.”
- There may be anxiety related to how they should appropriately react to the death or the rituals surrounding death.
- Physical manifestations such as nausea, headaches, body aches, and intestinal or menstrual disruptions are not uncommon.



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## Religion and Spirituality

All faith communities have active autistic members.

Autistic adults may have a deep sense of spirituality and/or religious belief. Non-speaking autistics may process and express their ideas about faith or spirituality by using pictures or symbols.

Some autistics may be spiritual without adhering to a specific religious tradition; for instance, many autistic adults find great solace and comfort in nature.

Many autistics have not felt welcomed by faith communities, and many have social anxiety which makes it difficult to participate in religious activities.



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## Social Stories

- Helpful tools, often in booklet form containing images and a few descriptive sentences per page
- Can help explain social situations in simple, concrete language
- Customizable social stories available at [Autismandgrief.org](http://Autismandgrief.org)



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## Learning Objective Recap

Identify how traditional religious beliefs and practices can present both benefits and barriers for adults with autism.



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## Learning Objective Recap

- Religion provides structure and order that often appeals to autistics.
- Religious organizations can provide significant community and social support.
- Religious rituals, services, or other memorial events may overwhelm autistics with sensory and social anxiety.



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## Learning Objective Recap

Discuss how spirituality may be expressed by adults with autism.



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## Learning Objective Recap

- Autistics may connect with their spirituality through music, art, nature or other experiences.
- Spirituality may be expressed privately, something kept as a personal experience.
- Adults on the spectrum, even if non-speaking, may express spirituality through traditional religious practice and ritual.



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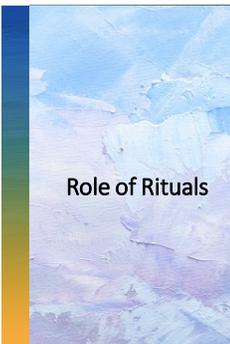
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From the beginning of civilization, humans have embraced the importance of rituals such as funerals and memorials.

Rituals help the bereaved in many ways, and they may be especially important in supporting a grieving autistic adult:

- *Psychologically*
- *Socially*
- *Spiritually*

Rituals are both cultural and religious.



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### Different Faith Traditions

After a death some people may attend a funeral or ritual of a faith tradition different from their own. This may be overwhelming or stressful for an autistic.

- Prepare them for what they might see and hear
- Explain how and why things may be different from their expectations



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### Recommendations for Rituals

- Strive for inclusion
- Appoint a supportive person to help during the funeral and other rituals
- Be sensitive to the ways autistics may be uncomfortable in faith communities
- Allow for attendance at some, all or none of the events or rituals



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### Recommendations for Rituals

- There are many ways to participate in both cultural and religious rituals, such as:
  - sending sympathy cards or flowers
  - making a donation in honor of the person
  - lighting a candle
  - saying prayers
- Communicate with the individual and their supportive network, if available, about what will happen at the events and what will be seen, heard, felt, and smelled.
- Share pictures of the places where the rituals will take place.



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## Ideas for Alternative Rituals

- Attend a private viewing
- Participate in a virtual viewing
- Participate in a private ritual, such as a day of remembrance
- Make a private visit to the cemetery
- Send a condolence card or flowers to the deceased's family
- Light a candle, look through a photo album, or make a memorial donation
- Visit a park, restaurant, or a place that is associated with the deceased



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## Learning Objective Recap

Delineate three techniques that clergy and others can utilize to assist autistics in navigating rituals.



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## Learning Objective Recap

- Prepare them for what they may see, hear and experience during the ritual.
- Include autistic adults in any events they wish to attend or participate.
- Provide support during the ritual. The ideal support person should be someone not intimately involved in the ritual, enabling them to completely focus on the autistic adult.



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## Disenfranchised Grief

**Grief that is not openly acknowledged, socially supported, or publicly mourned.**

**Even when it is unintentional, others may disenfranchise the grief of autistics by:**

- ignoring their emotional needs during a loved one's illness
- stigmatizing the manner of death such as suicide or overdose
- preventing them from saying goodbye or visiting at the end of the loved one's life
- attempting to force, guilt, or cajole the autistic into participating in rituals when they don't want to ("you must be there;" "don't you love the person;" "you'll regret it if you don't go to see them")
- choosing not to inform them about a life-limiting illness or death



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## Disenfranchised Grief

**Even when it is unintentional, others may disenfranchise the grief of autistics by:**

- not recognizing an important relationship (such as after the death of an LGBTQ spouse or partner)
- assuming they do not understand what is happening
- excluding them from funeral or memorial services
- blaming them for their "difficult" behaviors rather than understanding their behavior as reactions to a loss
- failing to recognize unexpected reactions, such as laughter, as indications of grief



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## Enfranchising Grief

**The ways professionals can enfranchise grief for an autistic adult should be individualized, but may include:**

- Creating opportunities for the individual to be included prior to (if known), or during and after the death
- Accepting any forms of communication an autistic person might use
- Including the grieving autistic as much, and as often, as they would like to be in both the planning for and attendance in the events and rituals that may surround the loss or death
- Being open to ideas that the autistic person may have about ritual, even if they are non-traditional
- Helping the autistic to visit their loved one's grave, especially if formal rituals have already happened, or the autistic was not included or able to participate
- Remembering the autistic should not be forced to participate, if that is their preference



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**The Ongoing Journey**

**Beyond the funeral, how can faith leaders support autistic grievers?**

- Educate your faith community about autism and its prevalence
- Use your faith's teachings to stress the value of inclusion
- Encourage inclusion by entire faith community
- Be aware of potential stressors for autistic adults, minimize stressors, and use your knowledge to respond appropriately



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**The Ongoing Journey**

**Beyond the funeral, how can faith leaders support autistic grievers?**

- Identify activities within your community that may be appealing to someone who is autistic; provide opportunities for inclusion
- Do not assume someone has autism or diagnose autism in your role, allow the person with autism to share their diagnosis if they choose
- Meet the autistic "where they are" regarding their faith beliefs



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**Learning Objective Recap**

Identify three possible ways to offer support to an adult with autism in faith communities, and through their grief journey beyond the immediate period of the funeral and burial.



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## Learning Objective Recap

- Create opportunities for ongoing grief support.
- Be aware of potential stressors for autistics and respond appropriately.
- Emphasize importance of inclusion within faith community.



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## More Resources and Information at AutismAndGrief.org



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### Program Highlights

Autism is a developmental disorder that, according to the CDC, affects one out of 45 adults in the U.S. Autism spectrum disorder affects communication, behavior, and cognition. It is not limited to one presentation and is highly variable. 40 to 50 percent of those with autism have some degree of intellectual disability and up to 30 percent are non-speaking or minimally verbal. Asperger syndrome, once its own diagnosis, is now considered part of autism spectrum disorder.



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### Program Highlights

Characteristics common to adults with autism include anxiousness, especially in social situations; difficulty interpreting the feelings of those around them; and needing to abide by a strict routine in their daily lives. Autistics tend to be direct and can seem blunt, rude and uninterested in others, typically not making eye contact when communicating with another person. They are logical thinkers, often develop passions in a single subject, and notice details that others may not. Because autistic individuals interpret language concretely, euphemisms should be avoided.



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### Program Highlights

Adults with autism may exhibit different reactions to death and loss than those typically exhibited by the neurotypical population, but this does not mean that they are not grieving. Autistics responding to loss may show little to no affect, feel disconnected from their emotions, be unable to identify their emotions, or engage in increased self-soothing behaviors. In grief, as with other stress-inducing situations, an adult with autism may repeat words or a phrase spoken by someone else or experience physical manifestations of grief, such as stomach aches and nausea that they and others fail to associate with a grief reaction.



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### Program Highlights

Grief is a universal human experience and not limited to neurotypical individuals. Grief does not occur in stages but is instead a highly variable experience for autistics and neurotypicals. Even within families, different styles or expressions of grief may cause conflict and misunderstanding. The experience of loss is most often discussed in relation to the death of loved ones yet also includes other significant losses – the death of an animal companion for example, and non-death losses, such as the loss of an important pastime or a friend or caregiver who relocates. Professionals should never assume that grief is absent due to a lack of outward emotion or behavior that may seem incongruous and should be aware of changes in behavior and previous functionality that may indicate grief.



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## Program Highlights

Clergy and other professionals working with adults with autism can increase their expertise and inclusivity by understanding how autistic adults grieve and how they can be supportive of autistics. Doing this requires application of a basic awareness of both autism and evidence-based research around grief and loss. In addition, clergy and others in professional support roles can help grieving autistics by modeling behavior that acknowledges the grief experience of autistic adults and an awareness of the differences between neurotypical grief experiences and autistic grief experiences.



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## Program Highlights

Several significant ways to support a grieving autistic adult include adequately preparing them and including them in rituals, supporting non-traditional rituals if preferred, removing barriers and stressors that may make autistics feel unwelcome in a faith community, including them in faith-based activities where they may establish a support network, and perhaps most importantly, understanding that autistics can be deeply religious or spiritual. Creating opportunities for inclusion in a faith community and ongoing grief support acknowledges their humanity and the vulnerability shared by all of us.



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