



## **Autism & Grief**

The grief experiences of people with autism are frequently misunderstood, belittled, and devalued. Comments such as “they can’t understand” and “no need to upset them” are common. In fact, people all along the autism spectrum grieve just like neurotypical people. They love and suffer loss in profound ways.

Though autistic grief reactions may appear to differ from those of neurotypical grievers, the loss of a loved one and the pain of grief that follows can deeply affect and alter an autistic’s life experience.

### **You Know an Adult with Autism**

Professionals in a range of roles and disciplines have a high probability of interacting with someone on the autism spectrum, in their professional capacities and/or in their personal lives.

The Centers for Disease Control and Prevention estimates that one in 45 adults in the United States is autistic (CDC, May 2020). Autism is a disorder that may affect an individual’s behavior, communication, 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.

Autistic individuals have a range of support needs; some may appear to need little or no assistance, while others may clearly require a great deal of support. Some autistics live independently and may have little to no network of family and friends; others live with family or in other supportive environments for most of their adult lives.

Historically, autistics have been misunderstood, misdiagnosed, and forced to live in overly or inappropriately restrictive environments. These histories may engender distrust when interacting with others, particularly with professionals.

Because symptoms of autism first appear in childhood, most new diagnoses today are pediatric. However, autism is a lifelong disorder, and autistic children grow up to become autistic adults. The statistic that one in 45 adults in the United States is autistic means there are currently 5.4 million adults with autism in the U.S. (CDC, May 2020). By 2027, about a million more children and teenagers currently diagnosed with autism will become adults (Autism Speaks, 2017).

While children and young adults are much more likely to be diagnosed today, many older adults—due to an earlier lack of knowledge in the medical community or lack of



healthcare access—may have never received a formal autism diagnosis. Some have diagnosed themselves based on extensive research, and others may navigate the world for their whole lives without an accurate diagnosis.

## **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 challenging to make and keep friends;
- seeming blunt, rude, or not interested in others (even when this is not the intention);
- 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;
- invading the personal space of others, or becoming very upset if someone touches them or invades their personal space;
- noticing small details, patterns, smells, or sounds that others do not;
- pursuing a keen interest in certain subjects or activities;
- being logical thinkers, sometimes preferring to plan daily activities carefully before doing them.

*(adapted from the UK National Health Service, 2019)*

All of the above characteristics, and more, can affect an autistic’s grief experience and responses. Although the individual’s ability to perceive or express emotions may differ from that of a neurotypical person, all autistics feel and some may be able to discern their emotions. One challenge that can arise in social interactions is when a neurotypical person’s perception that an autistic person’s emotional expression is mismatched to the situation. Such an unexpected response can lead to a misperception that the autistic lacks empathy, when it simply may be the individual’s unique emotional reaction. To neurotypicals, this apparent mismatch may be especially noticeable in grief reactions.



## **Grief Reactions in Adults with Autism**

Grief may cause emotional, behavioral, physical, and cognitive responses in autistic adults similar to those seen in the neurotypical population. Responses to grief can be affected by one's understanding and ability to communicate. For some people with autism, coping with the abstract nature of death can be difficult. As many autistics are very concrete thinkers, it may be possible to grasp that a person is gone but more difficult to identify and express feelings about the absence. Some adults on the autism spectrum may experience a delayed emotional reaction to loss.

Grief for autistics **may** result in:

- No outward change in behavior or a lack of affect can be characteristic of autism, with or without a loss. In both autistic and neurotypical grievers this response should not be mistaken for a lack of understanding or sadness.
- Regression, anxiety, and stress resulting in a feeling of disconnection from their own emotions and/or not feeling what they think others expect them to feel.
- 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.
- Rumination about a death or circumstances surrounding the death, causing the person to feel “stuck.” Rumination is a common characteristic of autism, and an experience of a loss may magnify that tendency. For example—especially in cases of sudden or violent death—an autistic individual might imagine the situation surrounding the death playing repeatedly, like a constant loop in their thought processes. (This is also not uncommon for traumatized neurotypical grievers.)
- Increased *echolalia*, a term that describes “echoing” or repeating a word or phrase spoken by someone else.
- An inability to express, describe, or identify emotions. Known as *alexithymia*, this condition is not confined to the autistic population but is often experienced by autistics.
- Anxiety related to how to appropriately react to the death or the rituals surrounding death. These concerns might include how and what to communicate

# **Autism & Grief Project**

## **Resources for Clergy & Professionals**

### **About Autism & Grief**

---



- about the death and/or their feelings; how to dress or behave in a setting such as a memorial service or funeral; how to respond to strong outward emotions from other mourners; or how their life may change as a result of the death.
- Physical manifestations such as nausea, headaches, body aches, and intestinal or menstrual disruptions are common among autistic and neurotypical grievers alike, although they may be experienced differently.
- Sleep disruptions such as increased napping, difficulty staying awake, nighttime arousals, and/or insomnia. Nighttime enuresis (bed-wetting) may also occur due to disrupted circadian rhythms and altered timing of sleep patterns.

Religious and spiritual questions often arise when dealing with death, loss, and grief. Many autistics may have this experience, especially those who have spiritual and/or religious beliefs or are a part of a faith-based community.

### **Spectrum Variations**

According to the most recent edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, autism spectrum disorder includes a wide range of presentations, which in turn impact the ways in which individuals with autism experience the world. In a change from previous editions, Asperger syndrome is no longer a separate diagnosis; those with Asperger's are considered autistic and sometimes referred to as having "low support needs" although in reality their support needs differ from those with "classic" autism and often are not publicly apparent.

Due to the range of the autism spectrum, as well as each person's life experience, it can be helpful to remember the insight of Dr. Stephen Shore, an autistic professor of special education at Adelphi University: "When you've met one person with autism, you've met *one* person with autism."

Between 25–30% of people with autism are non-speaking or minimally verbal, meaning they do not use spoken language to communicate (Tager-Flusberg, 2013). It is important to remember that these individuals do not necessarily have a cognitive impairment. Non-speaking adults may use augmentative and alternative communication (AAC) systems, Picture Exchange Communication System (PECS), adaptive technologies, or other tools to communicate. When meeting a grieving autistic who is non-speaking, always assume they understand you unless they indicate otherwise, and speak directly to them rather than to others who may accompany them.

About 40–50% of autistics have some degree of intellectual and developmental disability (IDD) (Charman, 2011). While cognitive understanding of complex issues such

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# ***Autism & Grief Project***

## **Resources for Clergy & Professionals**

### ***About Autism & Grief***

---



as death and grief may be more difficult for autistic adults with IDD, they are not children and should not be treated as such; their many years of lived experience should be respected and acknowledged.

Those who fit an Asperger profile may be referred to as requiring little support; however, their needs are not necessarily low but rather different. They often are able to live independently, which may mean they have a small support network. Yet these adults may still need help or guidance with tasks that require executive functioning skills, those organizational skills which help people perform activities such as keeping up with a job, owning a car or home, paying bills, and maintaining mental and physical health. They sometimes experience minimal support in relationships as well, and as a result may end up alone. Adults who fit this profile have the highest rate of suicide in the autistic population. They typically are very aware that they don't fit in, regularly experience negative social interactions, often have limited to no support from others, and struggle in many areas of their lives.

Each autistic should be seen as a whole person, not a sum of their features, behaviors, or diagnoses.

### **Guidelines for Interacting with a Grieving Autistic Adult**

As a professional, it is important to meet each person “where they are.” This includes people with autism. Even if one is uncomfortable or unfamiliar with an individual, professional etiquette must be maintained. Autistic adults should be granted the same level of respect granted to any adult.

Here are a few basic guidelines to remember when speaking to and supporting a grieving autistic.

- Do not talk about anyone in the third person in their presence (unless that is their preference) or speak to others as though the autistic was not there.
- Communicate directly with the individual—not to their family, direct support professional, or others around them. If you are unsure about the best method of communication, ask.
- Asking simple, straightforward questions that require straightforward answers may be helpful; provide ample time for the autistic to respond. Be aware that behaviors also serve as a form of communication.

# ***Autism & Grief Project***

## **Resources for Clergy & Professionals**

### ***About Autism & Grief***

---



- Individuals with autism may use communication methods that are visual, but this does not mean that individual is hearing impaired. Do not speak in a raised voice unless you know they are deaf, or if it is necessary due to a noisy environment.
- Autistic adults are adults. Do not talk “down” to them or use a childish voice. Speak clearly at their level of understanding and avoid euphemisms when speaking about death and grief. For example, saying “I’m sorry for your loss” may not be understood, because they may be confused by what you are sorry about when you were not responsible for the person’s death. Or there may be confusion about something being “lost;” someone died, they are not lost. A good rule of thumb is to be “straightforward, but not childish.”
- Do not be offended by, or attempt to correct, behavior you find out of place such as pacing, repetitive movements (also known as stimming), laughing at what you perceive as a sad situation, or echoing of your words. These behaviors may signal distress.
- Always assume an individual can hear and understand everything that is said, even if they cannot or do not respond at length, or respond in a way that seems unusual, inappropriate, or unexpected.
- Be aware of potential causes of sensory overload unique to each person. Sensory overload can affect a person’s ability to communicate and can interfere with the grieving process.
- If you can, try to learn something about an autistic griever’s family, living situation, and any support network they may have. These are the people who know them best and will be the greatest resources for you and the autistic throughout their grief journey.

### **Key Takeaways**

- Autism is common, and your community/constituency includes autistic adults.
- Grief affects people emotionally, spiritually, cognitively, and physically, and these responses are shared by autistic people who are grieving, even when they may not show it.
- Because many autistic adults have experienced trauma, working with them using a trauma-informed lens will be beneficial.

# **Autism & Grief Project**

## **Resources for Clergy & Professionals**

### **About Autism & Grief**

---



- Like all adults, autistic adults have accumulated knowledge about themselves. It's important to ask about and listen to them communicate about their needs, beliefs, and perspectives.
- Maintain your professional boundaries and be aware that autistics also have personal boundaries that should be respected. For example, they may prefer that you stand or sit four feet away rather than two feet. If you are unsure of their preferences, ask.

#### References

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