

Autism & Grief Project Fact Sheet



About Autism & Grief

The grief experiences of people with autism are frequently misunderstood, belittled, and disenfranchised. Comments such as, “They can’t understand” and “No need to upset them” are common. In fact, people with all subtypes of autism have the capacity to grieve deeply. They love and suffer loss in profound ways. Though their grief reactions may look different from those around them, the loss of a loved one and the pain of grief that follows can deeply affect and alter a person’s life experience. Adults with autism are people, too.

You Know an Adult with Autism

Professionals in a range of roles and disciplines have a high probability of interacting with a person with autism, either in their professional capacities 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 encompasses a broad range of behavioral, language, and cognitive differences. Autism is not limited to one presentation, symptom, or gene and is usually referred to as a “spectrum,” because of its high degree of variability.

Individuals with autism have a range of support needs; some may need little or no support, while others may need a high level of support. Some live independently and may have little to no support network; others live with family or in other supportive environments for most of their adult lifetimes.

Historically, autistic individuals have been misunderstood, misdiagnosed, and have lived in overly or inappropriately restrictive environments. These histories may impact trust and openness when adult autistics interact with others, particularly with professionals.

Because symptoms of autism first appear in childhood, most new diagnoses today are in children. However, autism is a lifelong disorder, and children with autism become adults with autism. The statistic that one in 45 US adults is autistic translates to 5.4 million US adults with autism (CDC, May 2020), and by 2027, about a million children and teenagers diagnosed with autism in the US will become adults (Autism Speaks, 2017).

While individuals 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 diagnosis of autism. Some have self-diagnosed, and others may navigate the world without a medical diagnosis.

Characteristics of Autism

While remembering that autism is an individual disorder that presents differently in each person, some common characteristics of autism include:

- finding it hard to understand what others are thinking or feeling
- getting very anxious about social situations
- finding it hard to make friends
- seeming blunt, rude, or not interested in others (even when this is not the intention)
- finding it hard to say how they feel
- taking things very literally – for example, may not understand sarcasm, or phrases like “break a leg”
- having the same routine every day and getting anxious if it changes
- not understanding social “rules,” such as not talking over people
- avoiding eye contact
- getting too close to other people, or getting very upset if someone touches or gets too physically close
- noticing small details, patterns, smells, or sounds that others do not
- having a very keen interest in certain subjects or activities
- being logical thinkers, liking to plan things carefully before doing them

(adapted from NHS UK, 2019)

All of the above characteristics, and more, can affect the grief experience. Although an autistic individual’s ability to perceive or express emotions may be different than someone without autism, people with autism feel and discern emotions. One of the challenges that can arise in social interactions is that the individual may express an emotion that seems mismatched to the situation. This interaction can lead to a misperception that the individual is not empathetic, when in fact it could be that a response triggered a different thought or memory. This reality may be especially noticeable in grief reactions.

Grief Reactions in Adults with Autism

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

Grief for individuals with autism may result in:

- No outward change in behavior or a lack of affect. As would be the case for neurotypical grievers, this response should not be mistaken for a lack of understanding or sadness.
- 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.” For example, in the case of a violent death, the person could imagine the circumstances like a loop in their thought processes (also not uncommon for 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 feelings related to the loss. Known as alexithymia, this condition is not confined to the autistic population but is often experienced by individuals with autism.
- Anxiety related to how they should appropriately react to the death or the rituals surrounding death. These concerns might include how and what to communicate about the death and/or their feelings; how to dress or act 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.
- Sleep disruptions are common during grief. Disruptions may include increased napping, difficulty staying awake, or 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. This may also be true for adults with autism, who may have spiritual and/or religious beliefs and may be part of a faith-based community. Visit the Religion, Spirituality, and the Role of Rituals section to learn more.

Spectrum Variations

According to the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), autism spectrum disorder (ASD) includes a wide range of phenotypes, which impact the way individuals with autism experience the world. In a change from previous versions, Asperger syndrome is no longer a separate diagnosis; those with Asperger’s are considered autistic and sometimes referred to as having low support needs.

Because this range of autism is also affected by each person’s life experience, it is important to remember former Asperger/Autism Network (AANE) Board President Dr.

Stephen Shore's often quoted perspective: "When you've met one person with autism, you've met one person with autism."

Between 25-30% (Tager-Flusberg, 2013) of people with autism are non-speaking or minimally verbal. This means they do not use spoken language to communicate. However, this does not necessarily mean these individuals have a cognitive impairment or are any less intelligent. Non-speaking adults may use augmentative and alternative communication (AAC) systems, Picture Exchange Communication System (PECS), adaptive technologies, or other tools to help them communicate. When meeting a grieving autistic adult who is non-speaking, always assume they understand and ask them questions directly, rather than asking others who may be accompanying them.

About 40-50% (Charman, 2011) of those with autism have some degree of intellectual disability (ID). While understanding complex issues such as death and grief may be more difficult, it is important to remember that autistic adults with ID are not children; their many years of lived experience should be respected and acknowledged.

Those who fit an Asperger's profile may be referred to as needing little support, however, their needs are not necessarily low but rather different. They are often able to live independently, which may mean they have little or no support network, yet they often need quite a bit of support. This is especially true in the areas of executive functioning that is required to keep up with a job, owning a car or home, paying bills, maintaining mental & physical health care, etc. They sometimes have minimal support in relationships as well; and as a result, may end up alone. Those who fit this profile have the highest rates of suicide among the autistic population—they are very aware that they don't fit in, have negative social interactions, often have limited to no support, and struggle in many areas of their lives.

Ultimately, it is key to treat every individual as a whole person, not a sum of their features, behaviors, or diagnoses.

Guidelines for Interacting with an Autistic Adult

As professionals, it is important to remember to meet each person "where they are." This truth includes people with autism. Even if uncomfortable or unfamiliar with an individual, professional etiquette and respect 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 person with autism.

- Do not talk about anyone in the third person in their presence (unless that is their preference), or as though the person was not there.
- Communicate directly with the person, not to their family, aides, or others around them. If unsure about the best method of communication, ask.
- Provide ample time for the autistic adult to respond. Provide time for them to express their emotions and be cognizant of behavior as a form of communication. Asking simple, straightforward questions that require simple answers may be helpful.

- Individuals with autism may have communication methods that are unfamiliar, but this does not mean an individual is hearing impaired. Do not speak in a raised voice as though an individual were hearing impaired (unless they are hearing impaired).
- Adults with autism are adults. Do not talk “down” to them or in a childish voice as though they are young children. Speak clearly at their level of understanding and avoid euphemisms when speaking about death and grief. For example, saying “sorry for your loss” may not be understood, because they may be confused about 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 “straightforward, but not childish.”
- Do not be offended by or corrective of 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 could 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 sensory overload that can be unique for each person. Sensory overload can affect a person’s ability to communicate and interfere with the grieving process.

Key Takeaways

- Autism is very common, and your community/constituency contains autistic adults.
- The things about grief that are universal or common in grief, such as the fact that grief affects people emotionally, spiritually, cognitively, and physically, include autistic people. These are universal, even when someone has support needs.
- Improving your own communication skills is key, both receptive and expressive.
- Because many adults with autism have experienced trauma in their life, being trauma-informed will be beneficial.
- If you know the characteristics of autism, you do not need to confirm the diagnosis. Use the tools provided on this website to guide your practice if you suspect autism.
- Autistic adults understand things about themselves, so it’s important to ask and listen to them communicate about their needs, beliefs, and perspectives.
- Be careful about boundaries; many autistic people have been socialized to tolerate boundary violations from professionals.
- Be aware of sensory sensitivities; many autistic people can be overwhelmed with lighting, sound, touch, people too close, temperature, colors, and smells.

Case Studies - Autism & Grief

Laurel is 23 years old and lives in a facility for adults with developmental disabilities. She attends classes in occupational therapy and is working on goals for achieving greater independence on tasks of daily living. She is highly attached to her father, but

he lives two hours away and visits infrequently. He has recently stopped visiting altogether and instead calls Laurel every few days. Due to the shift changes of rotating care providers, Laurel is frequently asking them when her father will be coming to visit, even though she has already been told he is unable to visit due to failing eyesight that limits his ability to drive at night. She calms down when told he will come “soon.” Unfortunately, when she then asks a different person who reminds her he can’t come anytime soon, she becomes argumentative and aggressive and slams doors or tips over chairs in her frustration.

Reflection Questions

- What behavioral strategies might you use to help Laurel when she is experiencing frustration?
 - How might you work with staff for greater continuity of care?
 - How could care plan be developed with look the goal of better connecting Laurel and her father?
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Michael, 35, and lives with his wife and three young children. He works as a software engineer and volunteers at his local church. He loves his children but finds it difficult to tolerate the general chaos that can come with children. Michael relies heavily on his wife to manage the day-to-day frustrations of keeping three kids clean, entertained, and behaved. Occasionally he is abrupt with his family but works diligently to not show anger in front of the kids. His wife has asked him to go to therapy with her, as she is feeling like a single parent even though he is a loving husband and father. Michael is resistant to going, as he sees no need to talk to a stranger about feelings and is honestly puzzled as to why his wife is constantly so distraught.

Reflection Questions

- Michael struggles to see his wife's point of view. How might you approach this in a counseling setting?
 - How might you help Michael verbalize his feelings, since he is resistant to sharing them?
 - Would role playing conversations be a good tactic for Michael and his wife? Why or why not?
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Cassie is a 21-year-old woman with high support needs who has lived with her grandmother her entire life. Following the death of her grandmother, Cassie is moved from California to Virginia to live with her Aunt Chrissy. While Cassie has a good relationship with her aunt, she reacts strongly to the myriad changes that all feel like they’re happening at once—the death of her beloved grandmother, a move, working with new providers, and having to develop a new routine. Initially, Cassie would repeat “Grandma’s coming back” over and over and would cry when Aunt Chrissy reminded her that Grandma had died. This pattern persisted for nearly a month until Cassie became fixated on watching the recorded livestream of the funeral. She grew quieter and more withdrawn. Her appetite diminished, and Aunt Chrissy could hear her

watching television late into the night. In the midst of this, a new paraprofessional named Kim began working with Cassie. Kim had seen similar reactions to death in previous clients and gently encouraged Cassie to complete her daily tasks, even if she didn't much feel like it. Kim and Cassie spend time walking near the pond close to Aunt Chrissy's home, and Cassie grew to love watching the ducks feed each evening. One evening, Cassie admitted that being able to watch the ducks at the pond made her remember her grandma, who had also loved bird watching. Little by little, Cassie's appetite returned, and she was able to sleep more easily at night.

Reflection Questions

- Name three manifestations of Cassie's grief.
- Describe Kim's approach to working with Cassie.
- What might be a next step for Cassie?

References:

(Charman et al 2011) The good practice report – Autism Education Trust
<https://www.autismeducationtrust.org.uk/shop/the-good-practice-report-charman-et-al-2011/>.

(Tager-Flusberg 2013) Minimally verbal school-aged children with autism spectrum disorder: the neglected end of the spectrum. *Autism research: official journal of the International Society for Autism Research* 6, 468–478.