



Rituals After a Death

As you assist an adult on the spectrum to prepare for a funeral, memorial service, or other rituals associated with a death, your commitment to their participation can offer important validation. Your efforts to include an autistic adult while also providing them with choices show respect for the adult and their grief, and, as importantly, respect the relationship the autistic had with the deceased.

From the beginning of civilization, there has been recognition of the value of rituals, such as funerals and memorials. In our modern world, different faith traditions continue to have meaningful rituals around death. Each family has its own death rituals and practices that draw from unique traditions, which include their spiritual, religious, or humanistic beliefs, and cultural and social backgrounds.

In some cases, these rituals may continue for a few days, such as a wake prior to a funeral service and burial, or a week of shiva. In many traditions, other rituals or events occur well after the death, such as an anniversary mass or a dedication of the memorial stone. Rituals can be an important part of the process of grieving and mourning. These structured events provide many opportunities for the autistic adult to choose whether to be involved.

It is equally essential to realize that while some autistics may find great comfort and purpose in rituals, some may not want to be involved with societal, religious, or cultural rituals. They may want to create their own ritual to honor the person, outside of societal traditions. In these cases, supportive understanding of an autistic person's aversion to such rituals is as necessary as efforts to be inclusive.

Pros and Cons of Rituals for Autistic Adults

Rituals impact our grief response in three main ways—psychologically, socially, and spiritually. There are pros and cons to consider when helping a person with autism think about whether to participate in rituals.

Psychologically

Pro: Rituals after death can help to confirm the reality of the death. This fact might be critical for autistics as it can provide tangible proof that the person has died. Funerals and other rituals also provide structured activities at an otherwise disorganized time.

Con: Without preparation and informed support by others, funerals and other rituals that involve groups and customs that are unfamiliar or uncomfortable may be psychologically draining for someone with autism. In addition, while rituals can provide structure, they also disrupt daily routines, which can be distressing.



Socially

Pro: Many people find comfort in mourning with others, and death rituals can provide that social support. Rituals bring family and friends together to mourn, share memories, thoughts, and feelings, as well as to celebrate the life of the person who died. Supportive family and friends can provide a balm to the wound of grief.

Con: Social expectations may be too much for the autistic person. Funerals and other rituals typically involve people gathering together, which also brings small talk, hugs, and displays of emotion, all or each of which may be difficult for a person with autism, provoking anxiety and sensory overload.

Spiritually

Pro: Religious death rituals can provide opportunities to receive solace and guidance from our faith tradition and link us with our cultural and spiritual traditions, particularly if religion is a part of the person's life experience.

Con: Many autistic people have a history of not belonging to or not being interested in organized religion. Understand that past experiences may hinder receiving solace and guidance from religious death rituals.

Include the Autistic in Decision Making

Whatever the rituals are, a person with autism should retain the choice to participate—or not to participate—in these events at their level of comfort. Given that many traditions include multiple events over several days, autistics may select to participate in some, all, or none of them. Communicate what will happen at the events and what and who they might see, hear, feel, and smell. Then provide the opportunity for them to make decisions about how they would like to be involved rather than arbitrarily including or excluding them. We all need opportunities to say our farewells in our own way.

While activities typically associated with a death can be challenging for individuals with autism, it is also entirely possible that an autistic person could navigate these potential challenges well, especially when their grief is acknowledged and supported.

Below you can find a list of questions for an autistic to consider when deciding whether and how to attend ritual events. These questions can be a helpful guide as you discuss the options for attending. If the decision is made to attend, it is important to appropriately prepare and to tailor the preparation to the individual.



Helpful Guidelines

Educate

If your loved one with autism has never been to a funeral or other death ritual event within your religious or cultural traditions, it is important to explain what will happen at the event and what they may experience. Individuals with autism are often very literal; so if the person who has died will be buried or cremated, the facts should be explained without euphemisms. These details may include seeing the body of the person who has died or an urn with cremains. You could visit the location beforehand to walk through what will happen and/or what they will see, smell, and touch at the place where the funeral or other service will be held.

Many religious traditions include beliefs in concepts such as angels and Heaven or an afterlife. It is important to recognize that for some autistic individuals, just as with neurotypical people, these may bring comfort, but for others, the abstract nature of these statements may be confusing. What matters is whether those beliefs are helpful to the individual.

Communicate

As always, be honest and clear about what to expect, using factual and direct language, avoiding euphemisms. Whether before or during the ritual, think about their senses and explain what and who they will see, what they will hear, what they might smell, what they might be able to touch. Offering clear, factual answers to questions about these situations is important. Many ritual events include a lot of people, many who may want to give the person with autism a hug or shake their hand. Your autistic loved one might not be comfortable with this physical contact and should be supported and validated in their decision. They may also find it helpful to receive guidance about what clothes to wear (but also helpful to have their choice of clothing accepted), how they may choose to interact with others, or what to say if they want to participate in the ritual by sharing a poem or special memory of the person who died.

Model

Depending on the needs and challenges of the autistic, it may be helpful to model responses to comments and situations that may be encountered at a funeral or other event. Because autism can make it hard to effectively respond to social cues, you may want to prepare the person by rehearsing responses to other mourners' sympathetic comments and gestures. This practice may help alleviate some of the social anxiety related to attending.



Offer Choices

To the degree possible, allow the individual with autism to decide how they wish to be involved in any ritual event at their level of comfort. Consider whether they can have a role such as being a pallbearer, playing an instrument, or handing out memorial pamphlets, and offer a choice. Respect their choices and provide options at any time during the process if they begin to feel uncomfortable. If people are expected to take communion at a memorial Mass or kneel in front of an open casket or to throw a handful of earth onto the casket, explain the expectation and offer a choice. You might want to offer the option of arriving either significantly before the event and leaving early, arriving when the event is nearly finished to catch the end of it, or participating in only part of the event.

Support

Be sure that the autistic adult has the opportunity to choose people who can be present and supportive with them during rituals, especially if family members or other regular members of their supportive network will be actively involved with the event. Anticipate the kinds of support needed and plan for it. If they require a schedule, create one and build in breaks. Ask them if having an item of comfort such as a fidget item or water bottle will be helpful. Let them decide what to bring.

Process

Be available after the events conclude to help your loved one with autism process their experiences. While you may gently inquire about their responses, be respectful of their freedom to decide whether and when they want or need to share their reactions.

Alternatives to Consider when Attending is not Possible

While self-determination and inclusion are strongly valued, there may be some situations where your loved one with autism may be too upset or uncomfortable to benefit from attending the ritual. In situations where the autistic adult decides they do not want to participate, it could be helpful to consider an alternate ritual.

Some possibilities that may be valuable include:

- attending a private viewing,
- participating in a virtual viewing,
- making a private visit to the cemetery,
- sending a condolence card or flowers to the deceased's family,
- lighting a candle, looking at a photo album, or making a memorial donation,
- visiting a park, restaurant, or a place that is associated with the deceased, or
- holding a small remembrance gathering of family and/or friends.

Autism & Grief Project

Resources for Family, Friends & Direct Support Professionals

Rituals After a Death



As many people have experienced during COVID-19, virtual funerals and memorial services are now common. This may be a good option if the autistic does not want to attend the event or cannot get there.

It is crucial that an autistic adult is involved with choosing and planning the way they would like to remember the loved one who died or in developing their own rituals. For example, you might help them find ways to remember their deceased loved one at special events and holidays by:

- lighting a candle,
- watching their loved one's favorite movie,
- offering a toast or a prayer,
- cooking their loved one's favorite meal, or
- observing a moment of silence.

Anniversaries of a death or loss can also trigger strong emotions. Consult the adult with autism about whether and how they would like to observe those dates. For example, they may want to:

- join a walkathon to promote awareness of suicide or cancer sometime after the death,
- participate in a book drive, or
- plant a tree in memory of a loved one.

Encouraging Inclusion and Understanding from Others

While increasing numbers of people with autism are integrated into their families and communities, unfortunately there are still people for whom autism is unfamiliar and uncomfortable. Although there has been an increase in research, education, and knowledge about autism and intellectual and developmental disability, a previous lack of understanding—as well as social separation created by institutionalization—has allowed some people to maintain outdated opinions about the capacities, potential, and needs of autistics. This outdated thinking may lead some people to question the inclusion of an autistic, their participation in funerals and other rituals, or their understanding of death.

When planning for death rituals like funerals and memorial services, you may encounter family members or funeral service professionals who try to prevent your loved one from fully participating. You may also encounter those who make unhelpful comments or who speak as if the autistic adult isn't present.



Helpful Tips for Responding to Others

It is important that adults on the spectrum be included as much or as little as they desire; it may be necessary to explain this priority to those who feel differently. Here are some suggestions for responding:

- Emphasize how important it is emotionally for someone to participate in the ritual as a way of sharing and recognizing grief even if it is unclear how much they cognitively understand. It may be useful to remind the unhelpful person that many others who participate also may not understand everything that is happening.
- Set firm and clear expectations. Phrases like “he is a member of the family and will be there” or “she’s her granddaughter and will be with us in the front row” help to set a tone of inclusion. You can also say, “Thank you but we will take care of ___.”
- Your autistic loved one may need movement breaks during a service or may vocalize during quiet moments at a memorial service. Extended family and funeral professionals might not be familiar with either of those, so it’s important to normalize these behaviors in advance. Let them know what might occur, and that you’re not worried if it does.

Use the resources on this website to help others understand why it’s important to acknowledge a person’s grief, even when it looks different from their own. Please share any information that you feel will be helpful.

In times of grief, it’s important to remember that people may say awkward, hurtful, or insensitive things because they don’t know what to say. Sometimes they speak without thinking things through. Take care of yourself in those situations. You can respond by letting them know what would be comforting to you or the person with autism, or simply let them know that you see things differently. If the situation is particularly upsetting, consider talking with a supportive friend, relative, or professional. Try to remain present for the autistic adult even if you’re troubled, and try not to let unhelpful people upset you.