

# Autism & Grief Project

## The Role of Rituals Fact Sheet



### The Role of Rituals

As you help an adult on the spectrum prepare for a funeral, memorial service, or other rituals associated with a death, your commitment to provide inclusion and choice can offer important validation. Your efforts to include an autistic adult while also providing choice show respect for the adult and their grief, and, as importantly, respect the relationship the autistic person 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 autistic people may find great comfort and purpose in rituals, some may want nothing to do 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 attend rituals.

#### ***Psychologically***

**Pro:** Rituals after death can help to confirm the reality of the death. This fact might be critical for autistic adults 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 foreign 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 understanding organized religion. It would be supportive to understand past experiences that may hinder receiving solace and guidance from religious death rituals.

## **Include Your Autistic Loved One 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 many 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 excluding them from such choices. We all need opportunities to say our farewells in our own way. And, feeling included—rather than excluded—is usually how each of us wants to feel.

While activities typically associated with a death can be challenging for individuals with autism, it is also entirely possible that the autistic person navigates these potential challenges well, especially when their grief is acknowledged and supported. Click [here](#) to learn more about the importance of acknowledging grief.

A list of questions to consider when deciding to attend rituals events is included in this section. These questions can be a helpful guide as you discuss the options with your autistic loved one. Click the download image to view or download them. If the decision is made to attend, it is important to appropriately prepare your loved one. Naturally, you will need to tailor your preparation to the individual. Visit the Faith Rituals section for detailed information about faith rituals and a sample calendar for planning.

## Helpful Guidelines for Inclusion

### ***Educate***

If your loved one with autism has never been to a funeral or other death ritual event within your tradition, it is important to explain what will happen at the event and what they may experience. For example, you could visit the funeral home beforehand to walk through what will happen and/or what they will see, smell, and touch at the place where the funeral will be held. If the individual who has died will be buried or cremated, individuals with autism are often very literal, so the facts should be explained without euphemisms.

Many religious traditions include beliefs such as angels and the concept of 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. Visit the Faith Rituals section for a brief overview of different religious traditions.

### ***Communicate***

As always, be honest and clear about what to expect, using factual and direct language, avoiding euphemisms. 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. These details may include seeing the body of the person who has died or an urn with cremains. Preparing answers to questions about these situations with facts and clarity 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 have guidance about what clothes to wear (but also helpful to have acceptance about their choice of clothing), 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 adult, 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, handing out memorial pamphlets

and offer a choice. Respect their choices and provide options at any time in the process if they begin to feel uncomfortable. If they 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 build it in. If they require a schedule, create one and build in breaks. Ask them if having an item of comfort such as a stuffed animal or fidget or water bottle will be helpful and let them decide what to bring.

### ***Process***

Be available after the events conclude to help your loved one with autism process their experiences. While it is acceptable to gently inquire about their responses, be respectful of their freedom to decide when and if they are ready 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 at the ritual to benefit from the experience. In situations where families determine that including the autistic adult is not a viable option, or 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:

- 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
- Holding a small remembrance gathering of family and/or friends

As many people have experienced during COVID-19, virtual funerals and memorial services are now widely used. This may be a good option if the person does not want to attend the event, cannot get there, or if others object to the person's presence.

It is important 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—perhaps 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 or participate in a book drive or plant a tree in memory of a loved one.

## **Encouraging Inclusion and Understanding from Others**

While some people with autism are integrated into their families and communities there are still, unfortunately, people for whom autism is unfamiliar and uncomfortable. Although there has been an increase in research, education, and knowledge around autism and intellectual and developmental disabilities, the previous lack of understanding around these conditions, as well as the separateness created by institutionalization, has allowed some people to maintain outdated opinions about the capabilities, possibilities, and needs of autistic adults. This outdated thinking may lead some people to question a person with autism's inclusion and participation in funerals and rituals or their understanding of a 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; and it may be necessary to explain this priority to those who feel differently. Here are some suggestions for responding.

- Emphasize how important it is for someone to participate in the ritual as a way of sharing and recognizing grief even it is unclear how much someone cognitively understands. 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 \_\_\_”
- If your autistic loved one needs movement breaks during a service or vocalizes during quiet moments at a memorial, extended family and funeral professionals might not be familiar with either of those things, so it’s important to normalize behaviors from the very beginning. 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. [Click here](#) to learn about the importance of acknowledging grief.

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.