

# Autism & Grief Project

## Communicating the News of Death Fact Sheet



There is no doubt that being the bearer of bad news is an incredibly challenging role. Regardless of your connection to the person who died, it is always difficult to share the news of death. If you had a close relationship with the deceased, trying to balance your own shock and grief while communicating clearly with an autistic loved one can feel overwhelming.

Understanding the impact of grief can be helpful as you communicate with your loved one. Visit the Understanding Grief section to learn more.

### Delivering the News

Communicating with clear and honest language about what has happened in whatever way is most helpful for the individual is the goal. Using words such as “died” instead of euphemisms such as “passed away” will promote clarity and understanding. The social stories on this website may be helpful communication tools.

Do not expect someone with autism to react to news of death like a non-autistic. They could appear calm but be having an extreme reaction to the news of the death and may lose their ability to communicate, not react emotionally, or completely withdraw or ignore the information. Although each individual and situation is unique, some core principles are helpful:

- Communicate with respect — Be deliberate and clear with your words, avoiding euphemisms, and balance honesty and explanations with what you know about the person you’re speaking to. Tailor all communication toward their comprehension level. Don’t assume their understanding is childlike.
- Rely on prior interactions — What has worked in the past when communicating with the person? Consider your understanding of their needs when assessing the best way to help them cope with this new information about an illness or death.
- Offer choices for next steps — Let them choose how to cope with the next steps of their grieving process. Options should be given for how and when they want to communicate about it; how much they want to know about the circumstances; and choices about participating in the funeral or other rituals.
- Provide reassurance — Let them know that they will continue to be validated and supported and affirm that their bond with the person who has died can continue in many ways that may not be clear at the time. Autistics are logical thinkers and

this may not make sense, but the connection can continue through behaviors, traditions, and myriad other ways.

## **Manner of Death Can Impact Grief Reactions**

Depending on the type of death, different language or explanations can be helpful. Here are some suggestions:

### ***Death After Illness***

If you had the opportunity to talk about the possibility of the approaching death during the illness, that will make this conversation somewhat easier, but finality is always hard. At the time of death, share a reminder of their past experiences: "Remember that grandma was very sick for a long time. She died today."

Recognize that after someone's long illness, family members may struggle with conflicting feelings. They may wish the person was still alive while also being relieved that the suffering and a period of uncertainty has ended. Your autistic loved one may have been frightened by the physical changes they observed in the person who was dying, such as loss of hair, loss of weight, scars, or connections to tubes and monitors, that may prompt questions in the days and weeks following the death.

Provide choices and support related to when and whether to see the deceased before or during a funeral. If they are reluctant, offer alternatives such as a virtual viewing or looking at photographs. For some people, seeing the deceased's body is important. Communicate the options and let your loved one with autism make the choices. Trust their intuition and use it as your guide. Visit the Role of Rituals section to learn more. Offer an important object or memory of the person. For example, "I know that grandma wanted you to have this special blanket that the two of you put over your legs while you watched television."

### ***Substance Abuse Death***

Illicit drug use and abuse are difficult topics of conversation, particularly when they result in death. As with suicide, there is still much social stigma attached, which can result in deep emotional wounds for families and communities.

The current understanding of drug addiction is that it is a biological disease called substance use disorder. It has social implications for the person who is addicted, such as withdrawal from usual activities, fixation on how to get the next high, and/or denial that anything is wrong or that everything is under control. For some people, addiction is manageable and treatable; others will die from it. With this view of addiction as a disease, it can become somewhat easier to discuss death by overdose.

Communicate directly with your loved one about the facts of the disease and how it led to death: "Your cousin Mary had an addiction. Her addiction was a disease that made her sick, and she died this morning because of it."

Focus on facts without excessive detail and try to remain nonjudgmental in the discussion.

Prepare yourself to answer questions about the addiction and why it made the person so sick that they died. If you don't know something, it's okay to acknowledge that. If the autistic adult takes medication, you may need to clarify that most drugs are not addictive, nor do they cause harm or death if taken as prescribed. "Some drugs make a person healthier, but if a person takes too many at one time, they can become very sick and may die."

### ***Sudden Death***

When a loved one dies suddenly, we are often unable to prepare ourselves for the loss. Sudden death might be the result of a medical emergency or the result of an accident. You may not have all the information surrounding the circumstances of the death right away, leaving difficult questions that cannot be easily or quickly answered. These issues can be particularly challenging for a person with autism because there is significant comfort in routines and known, predictable experiences.

Repetition of the known facts and acknowledgement of the unknown will be key in sharing the news. Keep the message direct: "Last night Uncle Bob had a heart attack. His heart stopped working, and he died. We don't know why this happened."

News may need to be shared over and over throughout the course of a day or week (or longer) to reinforce the information as the individual processes it: "Remember how we talked about Uncle Bob's heart attack yesterday? His heart stopped working and he died. I'm still feeling sad about it. What do you think about what happened? Do you want to write about what you feel or draw what you feel?"

If your faith tradition includes an afterlife or belief in Heaven, keep statements about that as concrete as possible. Using phrases such as "Your uncle is in Heaven, but we can't go there right now" can be confusing, unless the individual understands the concept of Heaven. Use concrete phrases, rather than abstract phrases or those that refer to something that living people do, such as "he fell asleep in the Lord."

### ***Suicide Death***

Coping with the death of someone by suicide can be especially difficult. Unfortunately, social stigma still surrounds suicide and mental health, and many families feel uncertain about how to talk about it. We encourage you to lean into this struggle and talk about it as candidly as you are able. Breaking the stigma surrounding mental health happens one conversation at a time.

Expect competence, but you might need to define a few unfamiliar terms. Be prepared to explain that suicide means that a person took their own life, and that there are many reasons that people die by suicide, including issues associated with autism.

If the autistic adult deals with depression, association of depression with the rationale for the suicide can generate fear that they will behave similarly. For this reason, be cautious about associating a cause with the suicide. Similarly, if the suicide is assumed to be related to a break-up or loss of a job, it is important to be clear that taking one's life is not a usual response to these events. Emphasize that the autistic adult has support if they become upset or worried and name the people who can help. Repeat facts clearly and honestly while acknowledging the unknown. It's okay to share that you don't know exactly what happened or why.

While it's important to use clear language, with a suicide or violent death, it may be best to avoid specific details about the death, unless the individual asks about them. If the circumstances of the death are something that the person with autism may have already learned about, that reality should be acknowledged. That information may bring about fears or anxieties that need to be addressed. Hearing about someone who overdosed on drugs may cause anxiety around taking medication. The mechanism of death may create a graphic image in the mind of the autistic adult.

Reiterate that there is no blame with suicide. It is likely that no one could have changed the situation. Ultimately, it was the choice of the person to die by suicide. People who may have been aware of the potential for it may have tried to help, but it doesn't mean the outcome would have been prevented.

Different faiths have differing approaches to what happens in the afterlife for a person who has died by suicide. If your family is struggling with spiritual or religious questions, we encourage you to take things one step at a time, focusing on the basic facts of the death. Draw on your faith community's resources; you don't have to go it alone. Share the resources in this website with others. The section for clergy and professionals may be helpful to members of your faith community.

Suicide is a crisis in the autism community. It is a leading cause of pre-mature death for autistic people. The suicide rate for autistic people is more than three times higher than the general population. Having a candid conversation with your autistic loved one about whether they are having or have ever had suicidal thoughts may be a good idea after they have experienced the suicide of someone they knew.

### ***Violent Death***

While there is much overlap in sharing news of a sudden death and sharing news of a violent death, it's important to acknowledge that fear and a lost sense of safety can be part of the equation when coping with a violent death. Elements of shock, disbelief, and the need to repeat key information are the same in situations of either a sudden or violent death. However, with a violent death we are tasked with the additional piece of providing a reassurance of safety.

As often as you repeat the news of the death, accompany it directly with reassurance of physical safety: "Your friend Mark died. He was shot with a gun. But I'm here with you and want you to feel safe. Do you feel safe?"

Violent death might require interaction with police officers and other community professionals that may or may not have autism training. If possible, appoint a family member or caregiver to be a companion and advocate for your autistic loved one when dealing with these professionals. These caregivers or advocates can act as a buffer and provide support if needed.

In the days and weeks after a violent death, there may be circumstances that cause fear or bring questions. Flashing police or ambulance lights, sirens, or loud noises may cause anxiety for an autistic adult and/or bring up feelings about the experience all over again, causing rumination or other trauma-related triggers. In these especially challenging moments, reassurance of safety can be helpful to your loved one, as with anyone else. Redirecting them to focus their attention on a special interest or pleasurable activity may also be helpful.