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## Communicating the News of a Death

Professionals in a variety of fields may encounter circumstances that require communicating news of a death to an autistic adult. Sharing bad news is always difficult. Depending on your experience with death notifications and/or experience in communicating with adults on the spectrum, your comfort level with delivering death notifications to autistics may vary.

Remember to maintain boundaries in alignment with professional roles and consider the following guiding principles and examples of how to communicate news of a death to an autistic. It is also important to remember that each individual and situation is unique.

### Core Principles

A death in the life of an autistic adult may lead to significant changes; for instance, the death of a primary caregiver may result in the need for new caregiving arrangements. As a professional, be sensitive to the fact that these potential secondary losses may also cause grief reactions or be as traumatic as the death.

- **Use deliberate and clear language**, avoiding euphemisms. Be honest with comments and explanations. Use words like “died” instead of “passed away,” “gone to sleep,” or “went to heaven” to promote clarity and understanding. (A discussion of heaven or other faith beliefs may help the person cope with the death eventually but is likely unhelpful during the initial sharing of news, unless their religious beliefs are well known).
- **Do not question a lack of typical grief reactions** or suggest that they do not understand the information you have provided if they are not responding as a neurotypical person would. The autistic adult may show little or no reaction to news of the death.
- **Tailor all communication** and support toward the comprehension level of the individual. Don’t assume a person’s understanding is less than your own, including those who are non-speaking.
- **Rely on prior interactions** with the individual, and your understanding of their needs, to assess the best way to help them cope with this new information about a death. If you are unsure, ask others who know them well, such as family or support staff who may be available.
- **Be sensitive** about the amount of information provided. Too much information at once can be overwhelming. When a person is in shock or upset, they can only

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process so much at once. Allow space and time after sharing news of a death before providing detailed information about arrangements for disposition of the body or rituals.

- **Offer choices** on how to cope with the grieving process, including how and when the autistic wants to communicate about it; how much information they may want about the circumstances of the death; and options for participating, or not, in the funeral or other rituals. Visit to learn more.
- **Provide reassurance** that the person will continue to be validated and supported throughout their grieving process. Enlist the help of their supportive network of family, friends, and others whenever possible. If the person does not have a supportive network, they may look to you to answer questions about the death and what will happen next.
- **Provide concrete options** for help or support rather than offering open-ended ones. In the initial period after a death, individuals (whether autistic or neurotypical) often do not know what they need or would be helpful to them. For example, instead of saying “Can I bring you anything?” ask, “Would you like something to drink? Would you prefer coffee or water?” Instead of saying, “Let me know if I can do anything for you,” offer tangible support, such as, “Would it be okay if I came over on Saturday to bring groceries, do laundry, or mow the lawn?”

For some individuals, a death may lead to the need to relocate. Those helping or advocating on behalf of the autistic individual will need to educate themselves on the specific situation, important variables, and possible options as well as the individual’s most critical needs and preferences. Rights of self-determination will vary based on the state of residence, as well as the legal competency status of the individual. In all cases the legal rights of the individual must be respected, and freedom of choice should be protected as much as possible. In some situations, the individual may not be fully informed of their rights, so it may be wise to identify an expert in legal self-advocacy to support them.

### **Things to Consider with Type of Death**

In many situations, autistic adults cannot identify their feelings; this may be especially true following the potentially shocking news of a death. Their initial focus may be on resulting changes to their daily routines, life circumstances, or tasks that need to be completed following the death. Processing emotions, dealing with support people, or spending time with family may not be the primary areas of concern that an autistic may want and need to address following the news of a death. Different causes of death may also result in different grief responses.



### **Sudden Death**

In cases of sudden death, there is no time to prepare for the loss, which may lead to feelings of shock, as well as sadness or frustration that there was no chance to say goodbye. Validating these feelings can be helpful. Grievors may wonder or even ask, “Could this happen to me?” or have concerns about their own safety or the safety of others. Reassuring the person that they are safe and unlikely to experience the same event, and repeating this information and reassurance as often as needed, can help the autistic feel less afraid and unsure. When communicating with an autistic adult, keep things as concrete as possible, avoid euphemisms, and truthfully relay the facts as appropriate.

### **Death by Suicide**

Suicide deaths are often stigmatized and may be difficult to discuss and understand. When informing an autistic of a suicide death, it may be important to define terms like “suicide” and “depression.” The generally accepted phrase when describing this type of death is that someone has “died by suicide.” The phrase “committed suicide” is considered inappropriate as it furthers the stigma around the cause of death.

The complexity of a situation that leads a person to die by suicide means that searching for a cause or a clear understanding of why someone died by suicide is not useful, even though we all share a human impulse to ask questions and seek explanations about the inexplicable. Be open to questions and answer them as honestly and with as much information as appropriate, while also acknowledging the unknown. During initial discussions, it is best to avoid discussion of theology around suicide unless specifically asked. Those discussions can be held later if the mourner expresses an interest.

If the autistic is experiencing suicidal ideation, reach out to local mental health centers or, if they have one, their own therapist or counselor. The National Suicide Prevention Lifeline is staffed 24 hours a day at 800-273-8255; if the person is in immediate danger of harming themselves, call 911. If possible, remain with the person and stay on the line with authorities: explain the person in need is autistic and may react differently than expected to any intervention. Texting “HOME” to 741-741 will connect the person to the Crisis Text Line.

### **Substance Abuse Death**

Death due to substance abuse is often sudden but may not be unexpected if the deceased struggled with addiction for a long time. Explain that substance use disorder is a disease and that while some people recover, some die from it. Provide the facts without excessive detail but always be honest and open to questions. Many autistic



adults take one or more medications, so it is important to be sure that they understand the difference between responsible use of their medically prescribed drugs and the misuse of medications or other substances that may cause harm.

### **Violent Death**

Reactions to the news of a violent death may be similar to reactions to news of a sudden death but may include an additional layer of fear and anxiety. The griever may lose their sense of safety and worry about the possibility of a violent recurrence. This response can also occur when the autistic reads or hears of deaths due to injustice that they can relate to in some way (such as hate crimes, police brutality, murder-suicide, or domestic violence). Provide as much reassurance as is reasonable but be honest as well. Openness to questions and acknowledgment of the unknown is important.

### **Death After an Illness**

A death after an illness may come after a period of anticipatory grief. Even when the death is expected, it may feel sudden (“I thought she had more time”). It can be helpful to remind the autistic griever of prior death and/or non-death losses and the coping tools that were supportive and comforting in those situations. Grievers may have feelings of relief after a loss due to illness, such as “she’s not suffering anymore” or “I can have more time with my family members or my own activities now that I am not so focused on caregiving.” This response is to be expected and validating these feelings is important. On the other hand, if the autistic was providing care, the sudden absence of a schedule that caregiving provided can also result in anxiety due to the loss of structure and routine.

### **Things to Remember**

The death of a primary caregiver due to any cause may bring significant changes to the life of the autistic. As noted above, it is important to respect their choices about their future as much as possible and support them in creating a plan.

- The initial communication of a death may bring shock, uncertainty, and strong grief reactions for families, including individuals with autism.
- Being honest, clear, and supportive during these times is key in helping autistic adults cope.
- Use [www.autismandgrief.org](http://www.autismandgrief.org) for more resources, tips, and examples of how to help, both during the initial communication and throughout the grieving process.