

# Autism & Grief Project Fact Sheet



## Communicating the News of Death

Professionals may encounter circumstances that require communicating news of a death to an adult with autism. Sharing bad news is always difficult. Depending on experience with death notifications and/or experience in communicating with autistic adults, one's comfort level surrounding delivering death notifications to adults with autism will vary. Remembering to maintain boundaries in alignment with professional roles, below are some guiding principles and examples of how to communicate news of a death to individuals with autism. Remember that each situation is different.

### Core Principles

A death in the life of an autistic adult may lead to significant changes. For example, the death of a primary caregiver might result in logistical and practical arrangements for future caregiving. As a professional, be sensitive to the fact 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 components of a faith belief may help the person understand and cope with the death but is likely unhelpful during the initial sharing of news, unless cultural and religious traditions are known.)
- There may be little or no reaction to news of the death. Do not question an autistic adult about a lack of typical grief reactions or suggest that they do not understand the information you have provided if they are not behaving as a non-autistic person would.
- Tailor all communication and support toward the comprehension level of the person on the spectrum. Don't assume a person's understanding is less than your own, including those who are non-speaking.
- Rely on prior interactions with, and your understanding of the needs of, the individual to assess the best way to help them cope with this new information about a death. If unsure, ask others who might know them well, such as family or support staff, if available.
- Be sensitive to not offer too much information at once. When a person is in shock or upset, they can only process so much at any given time. Allow space and time after sharing news of a death before providing detailed information about arrangements.
- Offer choices on how to cope with the grieving process, including how and when the person wants to talk or communicate in other ways about it; how much

information they may want about the circumstances of the death; or options for participating (or not) in the funeral or other rituals.

- 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, if available, whenever possible. If they do not have a network, you may be their only source and may be able to help them find others who can provide answers to their questions.

For some individuals, the death may result in the need to relocate, or move to a new home or different living situation. Those helping or advocating on behalf of the individual will need to educate themselves on the specifics of the situational dynamics and variables, and the needs of the individual. Individual rights will vary based on the county, state, and legal competency status of the individual. In all cases, freedom of choice should be provided, and the legal rights of the individual respected. In some situations, the individual may not be fully informed of their rights, so it may be wise to engage an expert or legal consultant to help guide any decision and to support the individual. The social stories on this website may be helpful tools when communicating about a death.

Often in the initial period after a death, individuals (regardless of autism) do not know what would be helpful or what they need. Providing concrete options for help or support are more useful than open-ended ones. 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, “Would it be okay if I came over on Saturday to clean your fridge and bring groceries, do laundry, or mow the lawn?”

## **Things to Consider**

Here are some things to consider when communicating news of death in different circumstances. It is important to remember that oftentimes autistic adults cannot identify or are unaware of their feelings, especially following the potentially shocking news of a death. The initial focus may be on the impending 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 to address with an autistic person following the news of a death.

## **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. Grievers may also have concerns of “could this happen to me?” or others concerns about their own safety or the safety of others. Reassuring the person that they are safe and unlikely to experience the same event, repeating information and reassurance as often as needed, can help the autistic

adult feel less afraid and unsure. It is helpful when communicating with a person with autism to 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 adult of a suicide death it may be important to define terms like suicide and depression. The generally accepted phrase when discussing this type of death is “died by suicide.” The phrase “committed suicide” is considered inappropriate as it furthers the stigma around the cause of death.

Suicide is complex and it is not usually helpful to search for a “cause” or a clear understanding of “why” someone died by suicide. Yet it is human nature to want more understanding and to ask questions. Be open to questions and answer them as honestly and with as much information as appropriate, while also acknowledging the unknown. In initial discussions, it is best to avoid discussion of theology around suicide unless specifically asked.

If the autistic person themselves is experiencing suicidal ideation, reach out to local mental health centers or their counselor if they have one. 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, stay with the person or on the line with authorities and 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 a local crisis center.

## **Substance Abuse Death**

Death due to substance abuse is often sudden but may not be unexpected if the person struggled with addiction for a long period of time. Explain that substance use disorder is a disease and that while some people get better and recover, some do die from it. Provide the facts without excessive detail but always be honest and open to questions. Many adults with autism are themselves taking various medications. It is important to explain the differences between medicines that help them and the misuse of medications or other substances that cause harm.

## **Violent death**

Reactions to communication about a violent death may be similar to sudden deaths but possibly with an added layer of fear and anxiety. There may be a loss of a sense of safety and questions about violence happening again. This response can also occur when the adult with autism reads or hears of deaths due to injustice (such as hate crimes, police brutality, murder-suicide, or domestic violence) that they can relate to in some way. Provide as much reassurance as is reasonable but be honest as well. Openness to questions and acknowledgement of the unknown is important.

## Death After an Illness

A death after an illness may come after some period of anticipatory grief for the autistic adult. Even when the death is expected, it may also feel sudden (“I thought she had more time”). It can be helpful to remind the griever of prior death and/or non-death losses and their coping tools that were supportive and comforting in those situations. There may also be feelings of relief after an illness loss, such as “she’s not suffering anymore” or “I can have more time with my family members or activities now that I am not so focused on caregiving.” This response is to be expected, and validating these feelings for the person with autism is important. On the other hand, the sudden absence of a schedule that caregiving may have provided can also leave the autistic adult feeling anxious and without a structure that supplies comfort.

## Things to Remember

The death of a primary caregiver may bring significant changes to the adult with autism. It is important to respect the choices of the autistic person as much as possible and support them in creating a plan for their future.

The initial communication of a death may bring shock, uncertainty, and strong grief reactions for families, including individuals with autism. It is important to be honest, clear, and supportive during these times. Use this site for more resources, tips, and examples of how best to help, both during the initial communication and throughout the grieving process.

## Case Studies – Communicating the News of Death

Jean-Pierre, 32, lives at home with his parents and younger sister, Marguerite. Marguerite has struggled with substance use disorder for nearly a decade, and fatally overdosed on heroin in the early hours of the morning. Jean-Pierre discovered his sister’s body several hours later and felt confused and overwhelmed when his parents began screaming and called 911. The house filled with people Jean-Pierre didn’t know—police, firefighters, paramedics, and finally the medical examiner. He felt afraid, and his usual coping skills of bouncing on a small trampoline in his bedroom while humming didn’t seem to be working. Finally, he sat in his darkened bedroom closet rocking back and forth. A police detective found him there a while later, accompanied by Jean-Pierre’s favorite aunt. His Aunt Corrine sat with him as he communicated with the detective using his iPad text-to-speech program about what he had seen. The detective joined him on the bedroom floor, sitting for nearly an hour while she asked questions, and responded to Jean-Pierre’s questions as well. The detective was gentle, but direct. She told him that Marguerite had taken too many drugs, and that she had died. She acknowledged when she didn’t know the answer to some of his questions and gave him time to process what was going on. Aunt Corrine was pleased to see that the detective spoke directly to Jean-Pierre, and that she treated him respectfully as an adult. When the questions were done, the detective left, and Jean-Pierre had time to grieve privately with his aunt and parents.

*Reflection Questions*

- What aspects of Jean-Pierre's experience were triggering, and how did he cope with those elements?
- What are three things that are important to remember in working with a client or patient who uses technology to communicate?
- How might Aunt Corrine and Jean-Pierre's parents facilitate healthy grieving?

Ethan, 43, was at home when the hospital contacted him and his mother about his father's car accident. They quickly drove to the hospital and waited anxiously in a family waiting room of the emergency department. After only a few minutes, a doctor and chaplain came into the room and sat down in the chairs across from Ethan. His mother began to sob as the doctor explained that Ethan's father had been in a terrible wreck, that it took emergency responders a long time to free him from his car, and that he had been gravely injured in the crash. On the ambulance ride to the hospital, his heart had stopped, and despite their best efforts, his father had died. Ethan's mother continued to cry and moan, while Ethan sat as still as a statue, his face revealing none of the intense sadness he felt. The chaplain expressed his condolences to the family and asked both Ethan and his mother how he could best support them in that moment. "Please just sit here with me," Ethan said, and the chaplain did just that, providing solidarity and a ministry of presence. Ethan didn't want to talk or cry just then, and the chaplain and doctor gave him the space to simply sit quietly for a moment.

*Reflection Questions*

- Describe the difference in Ethan's and his mother's outward displays of grief.
- Did the hospital chaplain help Ethan in a way that worked for him? Why or why not?