



---

## **Disenfranchised Grief**

Disenfranchised grief is grief that is not openly acknowledged, socially supported, or publicly mourned. First described by Dr. Kenneth Doka (1989), the term is used to describe a grief experience marginalized by society. When grief is disenfranchised, complications in the grieving process can occur. These complications can be magnified for a person with autism as well as for people with intellectual and developmental disability.

Autistic adults are often disenfranchised in their everyday lives. They often are socially isolated or otherwise marginalized. This is particularly true if they find social situations challenging, if they choose not to engage socially, or if they also have an intellectual disability.

### **Losses that are frequently disenfranchised include:**

- the death of a beloved animal companion
- a non-death loss, such as loss of a job, special activity, or object; a move; or a divorce
- the loss of a caregiver, whether the autistic lives with family or in a congregate care setting
- the death of someone who was important in the griever's life, but the connection to that person was not known to others (this can be more likely when the individual does not live with family)
- the death of a celebrity or public figure, even when the connection to the celebrity is not understood by others
- a death from advanced age or prolonged illness when death has been expected
- a death that is stigmatized (for example, death by suicide)

### **How an Autistic Adult's Grief is Disenfranchised**

There are many ways that family members, friends, and others disenfranchise an autistic individual's grief. These include:

- ignoring their emotional needs during a loved one's illness
- stigmatizing the manner of death such as suicide or overdose
- preventing them from saying goodbye or visiting at the end of the loved one's life
- attempting to force, guilt, or cajole the autistic into participating when they don't want to ("you must be there;" "don't you love the person;" "you'll regret it if you don't go to see them")
- choosing not to inform them about a life-limiting illness or death
- not recognizing an important relationship (such as after the death of an LGBTQ spouse or partner)
- assuming they do not understand what is happening

# **Autism & Grief Project**

## **Resources for Clergy & Professionals**

### **Disenfranchised Grief**

---



- excluding them from funeral or memorial services
- blaming the individual for “difficult” behaviors rather than understanding them as reactions to a loss.
- failing to recognize unexpected reactions, such as laughter, as indications of grief

### **Responding to Disenfranchised Grief**

A professional’s responses can enfranchise grief for an autistic adult. These should be individualized, but may include:

- Supporting the individual to share their thoughts and feelings using their preferred form of communication
- Encouraging acceptance by clergy, funeral home staff, and other funeral attendees of any form of communication the autistic uses
- Advocating for the autistic to be included in activities prior to, during, and/or after a death. This could include:
  - caregiving for and/or visiting a loved one who is sick
  - helping, as able, to plan the memorial service or funeral
  - supporting attendance at any public ceremony, private/remote attendance if that would be more comfortable, or the opportunity to create their own ceremony
  - finding ways to honor the deceased such as writing a note to the deceased, placing flowers or special objects in the casket
  - providing opportunities for the autistic to share their memories of the deceased, such as art, writing, or other creative or spiritual expressions
- Helping the autistic to visit their loved one’s grave, especially if formal rituals have already happened, or the autistic was not included or able to participate
- Advocating for the autistic individual to not be forced to participate if that is their preference
- Validating the autistic adult’s experiences of loss and of disenfranchisement. For example, be open to ideas that the autistic person may have about ritual—even nontraditional ideas—and resist medicalizing or criticizing their expressions of grief.
- Providing reassurance and helping the autistic person to identify people to provide support, including relatives, friends, and clergy.

Reference: Doka, K.J. (1989). *Disenfranchised grief: recognizing hidden sorrow*. 347.

---