



## **Managing Grief Better: People with Intellectual Disabilities (2019)**

Part of life is facing loss and grief. In our communities, we have social events, support systems, and cultural rituals to help us cope with the death of someone from our lives. Sometimes adults try to protect children or persons with intellectual or developmental disabilities (IDD) from loss and grief. Often persons with IDD have had little education about death. They may not understand the concept. But, in fact, everyone needs supports when facing death and loss. Hiding death from persons with disabilities may lead to more significant future problems.

When a person with IDD has a death in their family, it is likely they will be aware of the person's absence and the sadness and whispered conversation of others in the family. Sometimes the family believes that the funeral would be too upsetting for the person with IDD. The person with IDD may feel excluded causing both confusion and fear. Denial of the loss is not surprising in these circumstances. Changes in the person's ordinary routines can be upsetting. Prolonged searching behavior and an increase in separation anxiety can be noted. Angry and aggressive reactions may occur in such a delayed way that others might not connect the reaction to the loss.

If the person's only caregiver dies, then the dependent person with IDD may urgently have to leave their home and never return. In this situation, he or she has lost personal support as well as home and familiar routines. It is critical for the person to have help with intense emotions, as well as providing understanding and skills for coping. Even when the loss is someone other than a caregiver, persons with IDD experience the loss and may need help understanding the change in their life.

Research has shown that some people with IDD may have a delayed or limited understanding of the aging and death process. The irreversibility, universality, and inevitability of death are difficult concepts to understand. The capacity to integrate their experiences and to learn from them may need sensitive assistance.

There is an important advocacy role for healthcare teams, funeral directors, care managers and social workers who can challenge and encourage caregivers and support providers to support persons with IDD through the bereavement process.

### **Points for Caregivers of Bereaved People with Intellectual Disabilities**

- 1. Be honest, include and involve**
- 2. Listen - be there with the bereaved person**
- 3. Actively seek out nonverbal rituals**
- 4. Respect photos and other mementos**
- 5. Minimize change**
- 6. Avoid assessment of skills**
- 7. Assist searching behavior**
- 8. Support the observance of anniversaries**
- 9. Seek bereavement specialists for behavioral changes**



1. **Be honest, include and involve** - Many caregivers find themselves unable to be honest or to include the person with IDD. The person should be offered the choice to attend the funeral or memorial service. If he or she is unable to choose because of cognitive limits, it is usually advisable to involve the person as fully as possible in all the rituals being arranged.
2. **Listen - be there** - Be available to listen and provide support. This must occur immediately after the death, and, most importantly, also in the weeks and months following. Understanding the permanence of death comes slowly, thus the person with IDD may experience delayed grief.
3. **Actively seek out nonverbal rituals** - The nonverbal rituals in most cultures are helpful to many of us. They are particularly helpful to people with IDD who cannot find comfort in the written or spoken word. Counseling picture books may be helpful in explaining what happens when someone dies.
4. **Respect photos and other mementoes** - In the early stages of bereavement it is common to avoid pictures, possessions and places associated with the person who died. As time passes, such mementoes may come to be treasured. Less avoidance of these treasures can provide a useful measure of how a person is resolving their grief. People with IDD should be helped to choose mementoes early and again at a later date when some emotional pain has subsided. Sometimes people make unexpected choices, but these should be respected.
5. **Minimize change** - It is advised to minimize changes in routine, accommodations or caregivers at a time of grief. Ideally, it is suggested that major changes should be avoided for at least one year.
6. **Avoid assessment** - If a caregiver has died, it may seem sensible to assess a person to plan the best service or support system. However, the acute experience of death may not be an accurate assessment if behavior and skills have regressed because of the emotional energy spent on grieving.
7. **Assist searching behavior** - By revisiting special places or the cemetery, caregivers can assist appropriate searching behavior and support emotional recovery. Hoarding may suggest that more help of this kind is required. As another example, the person who elopes may be trying to find their lost home and family.
8. **Support the observance of anniversaries** - Anniversary dates should be formally observed. Many religions have formal services a year after someone has died. This is especially helpful for an important loss.
9. **Seek specialist consultation if behavioral changes persist** - Consider referrals to bereavement specialists earlier, rather than later. It is important to make mental health referrals as soon as any serious grief reactions are noted, such as aggressive behavior, persistent irritability, mutism, loss of skills, inappropriate speech (i.e., repeated asking "where is Dad?"), self-injury, tearfulness and eloping. Combining grief and mental health specialists to support the person can be more effective together.

Adapted from: <https://www.intellectualdisability.info/mental-health/articles/managing-grief-better-people-with-intellectual-disabilities>