

DISABILITY AWARENESS:

MANAGING GRIEF BETTER FOR PEOPLE WITH INTELLECTUAL DISABILITIES

Source: <http://www.intellectualdisability.info/mental-health/managing-grief-better-people-with-intellectual-disabilities>

It is imperative that all people, including those with disabilities, are able to access the supports given in their culture to understand death and loss. The following recommendations are made to assist persons with disabilities in dealing with death and loss:

1. Be honest, include and involve. Many caregivers find themselves quite unable to be honest or to include and involve the person with a developmental disability. The person should be offered the choice of whether to attend the funeral or memorial service. If he or she is unable to choose directly because of cognitive limitations, it is usually advisable to involve the person as fully as possible in all the rituals being arranged.
2. Listen - be there. Being available to listen and provide support is essential. 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 a developmental disability may experience delayed grief.
3. Actively seek out nonverbal rituals. The nonverbal rituals with which most cultures surround death are helpful to many of us. They are particularly helpful to people with intellectual disabilities who cannot find solace 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 a bereavement it is quite common to avoid pictures and possessions and places which are associated with the person who died. As time passes, such mementoes may come to be treasured. Indeed, the reduction in avoidance of such cues can provide a useful measure toward resolution of grief. People with an intellectual disability should be helped to choose some mementoes, and this choice should be offered again at a later date when some of their emotional pain has subsided. Sometimes people make unexpected choices, but these should be respected.
5. Minimize change. It is advisable to minimize changes in routine and changes in accommodation or of caregivers at a time of grief. As a rule of thumb, we suggest major changes should be avoided for at least one year.
6. Avoid assessment. If a caregiver has died, it may seem sensible to assess an individual in order to "fit" him/her into the best service or support system. However, this can be the worst time to assess someone whose behavior and skills may have regressed because of the emotional energy being expended on grieving.
7. Assist searching behavior. By revisiting old haunts and going to the cemetery, caregivers can assist appropriate searching behavior to support emotional recovery. Hoarding behavior may suggest that more help of this kind is required. For example, the person who absconds or is found wandering may be trying to find their lost home and family.
8. Support the observance of anniversaries. Anniversaries should be formally observed. Many religions have formal services a year after someone has died. This is especially helpful at the time of the anniversary of an important loss.
9. Seek specialists for consultation if behavioral changes persist. Referrals for consultation with bereavement specialists are typically made very late. It is important to make referrals, especially 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., asking "where is Dad?" all the time), self-injury, tearfulness and absconding. A recent study of the efficacy of volunteer bereavement counseling and support for people with disabilities found significant improvements in mental health and behavior. On the other hand, specialists without specific experience in bereavement did not achieve the same success.

CONCLUSION:

People with disabilities have a right to participate fully in the grief and mourning process and in all of society's support systems and rituals associated with these losses. Concerted effort is needed to offer death education to professionals and to parent organizations so that they may become familiar with normal grief reactions and provide proper supports.

Death education can be introduced into the school and adult education curriculum for people with disabilities. Advice is needed to construct guidelines for special agencies to follow when a death does occur. This might include helping professional caregivers rehearse breaking the news of a death.

Practical plans to avoid immediate admission to residential care are required. The importance of ensuring that the bereaved person has some mementoes of their deceased relative must be remembered and advice on the importance of nonverbal rituals at the funeral may be helpful.

Bereavement counseling for people with intellectual disabilities should be made available routinely and not just when a maladaptive reaction has been recognized as grief. Both individual and group work with bereaved individuals may be helpful, particularly if nonverbal approaches, such as the use of counseling picture books, are available.