

Clinician's Corner

by Connie Ryan-Oakes and Allison Chant

Question: I am a therapist working with a family of adult children who have recently experienced the death of their mother. One of the children is a 45 year-old developmentally disabled man. His siblings are wondering how best to help him. What suggestions can you offer?

Response: Here are a few things that need consideration in beginning to think about helping this man and his family: What is the degree of disability for the brother? Does he have past experience dealing with death? Has he lived with his mother, another family member or in an institutionalized setting?

The degree of disability is important to consider. Developmental disabilities cover a broad range from mild difficulties to profound mental retardation with many disabilities. "The greater the handicap, the less likely the individual's grief will be recognized." (Hollins, 1995). Another factor to consider is the cognitive age of the person. A person who understands the world at a five year-old age level will make sense of death similarly to a five year-old. They will have similar questions and preconceived notions about death. Something that may alter this a bit is past experience with death.

If the brother has had previous experiences with death he may have more of an understanding of how funeral rituals, burials and post-funeral events will go. He should be included in these rituals or at least offered the option to participate. He will be aware of sadness of family members and of the absence of the parent. There is a tendency to want to protect the developmentally disabled person from the pain of grief. Excluding him does not do this, but instead leads to denial of the death, fear and confusion.

The setting in which the brother lives is also an important piece to consider. Has he lived with his mother or has he lived in a group home setting? If he has lived with his mother there will be the need to consider where he will live now that she has died. If this is the case, he may now have lost a parent and friend, his home and many possessions as well as the familiarity of his routines and neighborhood. If he has lived in a group home the death of the parent will not disrupt routine in the same way as it would at home. Because much of daily life remains the same, caregivers sometimes ignore or minimize the effects of losses.

Hollins (1995) offers the following for helping people with developmental disabilities cope with death and loss.

- ◆ *Be honest, include and involve:* The person should be offered the choice of attending or not attending the service. If unable to cognitively make this choice, involve the person as fully as possible in any ritual.
- ◆ *Listen, be there:* This is needed immediately after the death and also in the weeks and months to follow. The person may experience delayed grief due to a slower understanding of the permanence of death; continue to listen and offer support.
- ◆ *Seek out nonverbal rituals:* Solace isn't always found in spoken or written word. A counseling picture book may be helpful for explaining what happens when someone dies.
- ◆ *Respect mementos and photos:* Help the person choose photos and mementos that are special to him/her. Offer this option again at a later time when some of the pain has lessened. Respect unexpected choices, we all find different things meaningful.
- ◆ *Minimize change:* Change routine and caregiver situations as little as possible during the initial period of bereavement. Try to have as little change as possible in the first year.

◆ *Avoid assessment of skills:* Due to regression as a result of the loss, this is not a good time to assess a person's skills. Much energy is going toward grief and is less available for basic skills.

◆ *Assist in searching behavior:* Visiting places of importance, i.e., home and the cemetery, can be supportive for the emotional recovery process.

◆ *Observe anniversaries:* Many religions offer formal remembrances of those who have died, particularly at the anniversary.

◆ *Seek professional help if behavioral changes persist:* Referrals are often made late. Seek them out early if seeing serious grief reactions such as: aggressive behavior, self-injury, persistent irritability and loss of skills.

In conclusion, people with developmental disabilities have a right to fully participate in the grief process, in the support systems offered in society and in rituals created for these losses. In our work as therapists we can help families help their members with disabilities. Grief counseling should be available as a matter of routine, not only when a maladaptive reaction has been recognized as grief. Individual, family and group work can all be helpful in supporting people with developmental disabilities.

Resources

Hollins, S. (1995). *Managing grief better: People with developmental disabilities. The Habilitative Mental Healthcare Newsletter, (14)3.*

Luchterhand, C. & Murphy, N. (1998). *Helping adults with mental retardation grieve a death loss.* Accelerated Development.

Oswin, M. (1991). *Am I Allowed to Cry?* London: Souvenir Press (E & A) Ltd.

The New York State Office of Mental Retardation and Developmental Disabilities, 44 Holland Ave, Albany, NY 12229.

The National Association for the Dually Diagnosed. Contact 845-331-4336 or info@thenadd.org.