

## How to Help Adults With Developmental Disabilities Cope with Death

Whether the death is of a loved one or someone in the community, it is important that an adult with developmental disabilities be guided to an understanding of what has happened and what it means to them. It isn't always easy for caregivers to know how to help.

### What should we tell adults with developmental disabilities about death?

They should be told about the death by someone close to them, and they should be told the truth. An adult with a developmental disability's view of death is different dependent upon their cognitive and functional abilities. They need to understand that death has occurred, that it is final and that it is all right to express feelings.

Caregivers must encourage their loved ones to understand the reality of death. Healthy grieving for both caregiver and loved one depends on acknowledgement of tragedy, not denial.

### How does an adult with developmental disabilities react to death?

Adults with a developmental disability react to traumatic situations as any other adult would: with disbelief, bodily stress, anger, guilt, anxiety and panic. It is misleading, however, to suggest that adults with developmental disabilities will follow a predictable pattern. They often act out their feelings about death in ways that could seem inappropriate. In learning to cope, they may not be able to say what they feel in words and may depend on body language and behavior to vent feelings.

Adults with developmental disabilities may have unrealistic notions which prompt questions. Did I cause this to happen? Will I die too? What will happen to me now? Make sure they understand your answers, so that unnecessary fear can be avoided. Do not be surprised to see grief return on special occasions such as birthdays and holidays and during significant life events.

### How can adults with developmental disabilities be encouraged to express their grief?

Give them every opportunity to ask questions, discuss memories of the person who has died and unburden feelings. Don't be afraid of tears or angry reactions and to express your own grief in front of your loved one. Caregivers who openly express their own emotions free their family members to do the same.

Adults with developmental disabilities should feel safe to express their grief in their own way. They may express anger at the loved one for "leaving." Or they may make an honest statement like, "I'm glad it wasn't me." These reactions are normal. They need to know that it is acceptable to have and express such feelings.

Encourage them to reach out to adults other than their caregiver as well – a grandparent, aunt or uncle, clergy or counselor. For loved ones whose grief is deep and sustained, provide every opportunity to talk about their loss. Then help them to get involved in social activities.

Are there any reactions that can be harmful to my loved one?

Avoid telling an adult with developmental disabilities to “be brave” or “be strong” for the sake of children or a parent who is taking the death “badly.” Those who keep grief bottled up inside may develop more serious problems later. It’s better to be realistic and say, “Yes, it’s tough.” Or, “I feel bad too.” Family religious beliefs can provide needed strength and comfort.

Should my loved one attend the funeral?

An adult with developmental disabilities is an integral part of the family and should be included in significant occasions. For adults with developmental disabilities, the ceremony surrounding death is of enormous significance. They need to be given the choice to attend part or all of the services. If they will be attending the visitation or wake and funeral, explain in advance some of the details. Tell them what to expect if they may be viewing the body. Put them at ease by describing what will happen during the visitation or service so that they will understand why it is being done. Allow them to not attend.

When are reactions causes for concern?

Reactions such as regression, denial, inability to function and emotional disturbance are normal in grieving for a while following bereavement. However, reactions that persist or become extreme may indicate significant problems.

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