

RESPONDING TO GRIEF REACTIONS OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES



People with intellectual and developmental disabilities (IDD) are often not included in the usual conversations, cultural rituals, and other means of personal and/or communal acknowledgement of loss and grief. As a result, their grief reactions can be complicated or prolonged. Additionally, the language of grief for people with IDD, whether or not they are verbal by nature, is primarily behavioral. To help people process their grief, we first need to recognize it as the source of the thoughts, feelings, and fears which their actions convey. This resource is designed to help you identify specific situations grievers with IDD may experience and behavioral communications that may be grief-related. For each situation or communication, there is a strategy to employ that may promote healing.

SITUATION OR BEHAVIORAL COMMUNICATION

STRATEGIES TO ASSIST

The person was not able to attend the wake, funeral, or ethnic/cultural equivalent, or did not comprehend the meaning of the event.

Help the person conduct a goodbye ritual that is concrete and personally meaningful. A ritual acknowledges the person's loss and allows them to say goodbye.

You are not certain the person understands "death" or think they may have a simplified notion of it (e.g., not realize its permanence). Given their level of understanding, they may be confused if people seem hesitant to talk about it.

Describe death concretely. Avoid phrases like "passed on," "went to sleep," or "no longer with us." Do not avoid talking about "the what" and "the how" within reason. Use items or experiences to teach that the body "no longer works," "can't be fixed," and "the person won't come back."

The person may be feeling emotional pain unlike anything they have ever experienced, fearing it will never end but lacking the words to express it.

Acknowledge the pain and assure the person that they will not always feel it so strongly. Be a reflective listener to verbal and non-verbal communication. Avoid saying, "I know how you feel..."; "You have to be grown up about this..."; "What you need is..."; "You'd feel worse if...". It can help if you name the feeling: "You feel sad. You feel mad." A feelings chart may be helpful.

The person believes or fears that other people they know are now going to die.

Explain others are not going to die just because one did. Point out that people continue to be around. Use an example if available (i.e. "It's like when one of the fish in the tank dies, the others keep living.")



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The person may not know how to ask for information about what happened (or what will happen). Even the idea of asking for information may not occur to them.

In their grief, people may ask questions repeatedly. The same question may be asked often in a short period of time.

The person appears to be searching for the deceased. The search can be actual (looking in places) or virtual (talking about the person, asking for the person). They might say they saw the deceased person. This may have occurred in a dream or in their imagination, but the person was seen and was real to them.

Shortly after a known death or significant loss, a person begins to behave differently than they did prior to the event.

Grief causes fear

Grief causes anxiety

A new experience (personal or the witnessing of someone else's loss) renews the person's feelings of missing someone.

There is an observed increase in ritualized behavior.

Anniversary, holiday, birthday, or other significant event triggers grief response

The person may want to remember the deceased in a special way.

Help the person to ask questions: "Do you want to know about...?" and encourage them to do so. Notice when a person is trying to get information from you.

Keep answering the questions. It is the feelings of grief and not a lack of information that is causing the repetition.

Support the person in the search, but again explain the "foreverness" of death. Acknowledge the loss. You may want to ritualize another goodbye. Anniversaries, holidays, and seasons can trigger searching.

Reflect back to the person that their actions are a way of expressing the hurt and pain of grief: "You threw your clothes all over your room and broke those things because you're missing _____. I know you're hurting inside (touch your own heart to show hurt there)." Suggest doing one of the other grief processing activities.

Listen to the fears. Don't contradict or deny them, just acknowledge them. If fear persists over time, or interferes with life activities, refer the person for counseling.

Use deep breathing and other relaxation techniques.

Know that grief comes and goes and that there are numerous triggers for it. Respond to each cycle of grief in the same way you did the previous cycle. Each one will need healing as much as the one(s) before it.

Recognize that rituals provide security. Be aware that a ritual of comfort can arise out of any activity (taking a coffee break, looking at a photo album, etc.). Help the person maintain and practice the rituals they select.

Important "grief-triggering days" need to be anticipated and supported. Help the person carry out a memorial tribute or ritual to acknowledge the significance of the day.

Give the person choices about how to memorialize the person they lost and express their feelings. The choices may be expressed in action rather than words (pictures, dance, volunteering). Smell and taste are tied strongly to memory and are important tools in memorialization.

This resource reflects practice-based knowledge developed at The Boggs Center and informed by professional training and consultation, including the work of Robert L. Morasky, PhD. Preparation of this document was supported by the NJ Department of Human Services, Division of Developmental Disabilities. February, 2026