

RESPONDING TO GRIEF REACTIONS

OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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For many reasons, 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 of not being included, their grief reactions can be complicated and/or prolonged. Additionally, the language of grief for people with IDD, whether or not they are verbal by nature, is primarily behavioral. In order to help people process their grief, we first need to recognize it as the source of the thoughts, feelings, and/or fears which their actions convey. Below is a table designed to help you identify specific situations griever 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

The individual was not able to attend the wake or funeral or ethnic/cultural equivalent or did not comprehend the meaning of the event(s)

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

STRATEGIES TO ASSIST

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

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

SITUATION OR BEHAVIORAL COMMUNICATION

The individual may be feeling emotional pain that is unlike anything s/he has ever experienced and s/he may think/fear the pain will never go away but not have the words to express that fear

The individual believes/fears that other people s/he knows are now going to die

The individual 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 him/her

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

The individual 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)The individual says s/he saw the deceased person. This may have occurred in a dream or in his/her imagination, but the person was seen and was real to her/him

Shortly after a known death or significant loss, an individual begins to behave differently than s/he did prior to the event

STRATEGIES TO ASSIST

Acknowledge the pain and assure the person that s/he 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." Use of a feelings chart may be helpful.

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.")

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

Reflect back to the person that her/his 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..."

SITUATION OR BEHAVIORAL COMMUNICATION

STRATEGIES TO ASSIST

	...(cont'd) 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
Grief causes fear	Listen to the fears. Don't contradict or deny them, just acknowledge them. If fear persists over time, or interferes with life activities, refer for counseling
Grief causes anxiety	Use deep breathing and other relaxation techniques
A new experience (personal or the witnessing of someone else's loss) renews the individual's feelings of missing someone	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
There is an observed increase in ritualized behavior	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
Anniversary, holiday, birthday, etc.	Important "grief-triggering days" need to be anticipated and supported. Help the Individual carry out a memorial tribute/ritual to acknowledge the significance of the day
The individual may want to remember the deceased in a special way	Give him/her choices about how to memorialize the person and express his/her 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



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