

WHEN A LOVED ONE DIES FROM AN INFECTIOUS DISEASE

Death of a loved one is a painful experience. However, death due to an infectious disease outbreak may be more difficult for several reasons: the death is unanticipated and families may be separated from their hospitalized loved one due to potential contagion. Families may be unable to grieve and memorialize their loss in ways that are religiously and culturally familiar. It is likely that family and close friends will be distressed, confused,

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and have many questions.

When a loved one dies, we are forever changed. As we move through the pain of grief, it is important to remember that many people find new strengths and capabilities and develop enduring relationships with others.

This Fact Sheet provides helpful information to families (or those

caring for them) to help cope with their loss.

Circumstances Surrounding the Loss

Deaths due to an infectious disease outbreak may occur in several types of environments, such as hospitals, nursing and assisted living facilities, and at home. Many may die without their loved ones present, unable to hold their hand, or grieve at their bedside. It is expected that family members will want to know the circumstances surrounding the death. That information may not be immediately available and loved ones may experience delays or incomplete information.

When the News Comes

As much as one might be prepared for the death of a loved one, we are never ready to receive such news. Notification of a death is likely to come as a phone call from someone representing the place where the death occurred. That person may or may not be known to the family and might only have a few details about the death (e.g., time of death, who was with the patient at the time of death, and any final message from the deceased to their family). Additionally, family members are likely to be distressed and unable to pose questions to the notifier, often requiring additional contact after the initial notification.

In addition, the deceased's remains and personal belongings may not be quickly available, further distressing the family. For families whose religion or culture prescribes rituals for the management of the body, the absence of the body can be an additional loss.

Adult family members should properly explain the circumstances of the death to children using simple and

clear language that is developmentally appropriate for each child. The nature of a child's relationship to the deceased and age will likely determine the intensity of their responses. Older children and teenagers may have more questions, and family members need to be prepared to share information in a calm and clear manner. Families may want to seek professional help to understand how best to inform and support children when someone close to them dies. This could be either face-to-face or virtual.

Initial Reactions

Grief is a normal and expected reaction to the loss of a loved one. There are many ways to grieve, including emotional reactions ranging from stunned disbelief, to great sadness or rage. There is no "right" way to express grief, especially immediately after notification when the news is fresh and feelings are raw. Due to potential physical and emotional separation due to the infectious disease outbreak, family members may have been out of contact with the deceased, so the death may feel less "real." When individuals cannot share their grief with others in ways that provide comfort and validation, they may feel that their grief is not shared or acknowledged. When grief goes unacknowledged, people may experience disenfranchised grief, or that their grieving is unvalued, resulting in feelings of helplessness and powerlessness.

Grief impacts us in nearly all aspects of our lives:

- Cognitive — Problems remembering, concentrating, prioritizing

Continued

- Emotional — Strong feelings of sadness, anger, guilt, loneliness and even joy in remembering
- Behavioral — Increased/decreased activity
- Spiritual — Questioning faith or increased religious activities
- Social — Craving being alone or with others
- Physical — Fatigue, sleep difficulties, appetite changes
- Secondary loss — financial insecurity or loss

Collective Grief

How people express grief is influenced by culture. Cultures vary in acceptance of intense displays of emotion and sharing of feelings and difficulties. It is most helpful to offer support, respect, and recognition of cultural rituals for grieving families. It is important for people to grieve together, even when they are unable to be together physically. Family members can receive support from each other, as well as friends and mental health professionals (e.g., grief counselors or chaplains). Support can be provided “virtually” through phone calls, texts, emails, and video chat, and all these modalities should be encouraged.

Families are encouraged to consider options for memorials and burials at a time when family members can be together. It may be necessary to modify traditional memorialization practices. Importantly, memorialization offers comforting ways to be together and mourn loved ones.

Grief Adaptation

Grief can be a prolonged process that is neither linear nor predictable. Acute grief is raw, disorganizing, and highly emotional, however, intensity of grief usually diminishes over the first year after the death. Although grief never really “ends”, with time it usually becomes a less central and dominating part of one’s life. However, in certain circumstances (e.g., sudden or violent deaths) the intensity of acute grief can continue unabated, at times requiring intervention.

Those bereaved by infectious disease are encouraged to reach out to others to both receive and offer support. Being open and honest will encourage others to do the same, creating important connections. Practicing good self-care (e.g., eating properly, exercising, maintaining good sleep hygiene) supports health, well-being, and resilience. Bereaved persons are encouraged to seek help when required, including formal help from trusted health care providers or mental health professionals, such as the Disaster Distress Helpline (1-800-985-5990).