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Office of Integrated Health Health & Safety Alert/Information

Grief and Loss Health and Safety Alert

What is Grief?

Grief is a normal physical and emotional response to the loss of someone or something (16). Another term used to describe grief and loss is bereavement, which means to be deprived. Grieving is a human reaction to loss of life, or extreme changes to daily life, or routines, which upsets their feelings of security and comfort (2). People experience grief whether the death or loss was expected or unexpected. Grief can also be experienced after a disaster or another traumatic event, such as the pandemic or hurricane.

Even if the person did not know anyone who perished personally, and/or the person was not physically present for the event, a person can still experience grief and feelings of loss. Grief can also happen in response to drastic changes in someone's life, such as a loss of a job, loss of support, or the loss of a person's home or personal belongings due to a natural disaster.

Everyone reacts differently to grief, but some common grief reactions include:

- Shock, disbelief, or denial.
- Anxiety or increased worry.
- Distress or feelings of helplessness.
- Anger or irritability.
- Periods of sadness and depression.
- Loss of sleep and loss of appetite.
- Frequent and/or extended periods of crying (2).



Stages of Grief - Kubler-Ross Model

There are several different models of the stages of grief. The most frequently used is the Kubler-Ross model, developed in 1969 and published by Elizabeth Kubler-Ross in the book entitled, *“On Death and Dying”* (12).

While the Kubler-Ross model breaks grief down into the following stages, these stages do not happen in any specific order, several may be experienced at the same time, and vary in length from person to person. The Kubler-Ross model is well-known and used among the healthcare professionals to describe the stages of grief an individual may be experiencing.

Denial –

The first stages in the grieving process is denial. A person or family member may not believe the diagnosis or death of someone they care about. The first reaction may be disbelief of the terminal diagnoses, and/or questioning the results of testing the individual received. Keep information straightforward and factual. Individuals need to be given some time to absorb the information and process it at their own pace (6).

Anger –

In this stage, the individual may feel angry towards medical professionals, family members, their God, caregivers, or even themselves. They question if enough was done to prevent the illness, disaster, death, etc. They believe their God has deserted them or the loss is associated with some form of punishment. There may be anger towards government officials for decisions regarding public safety which limited travel and gatherings (7).

Bargaining –

In the bargaining stage of grieving, some people may bargain with medical professionals, and others may bargain with their God. The person is typically contemplating how they got to this place or event and struggling with how to control the situation moving forward. It is common for people to wonder if an outcome would be different if they had made other choices. This bargaining may be a last attempt at following medical recommendations, desperately seeking alternative medical treatments or opinions, or making a “deal” with their God for a miracle. While this is normal, it is important to listen to the trusted people around you to help think through decisions made while in this stage (6).

Depression –

In this stage of the grieving process, feelings of sadness, hopelessness, and being unable to feel pleasure or joy are common. Some may also experience tiredness and may avoid others to isolate. Depression is a common feeling but can lead to more severe thoughts such as wishing to join a person in death. It is important to seek professional help if those thoughts persist. (6).

Acceptance –

Typically, the last stage of the grieving process is acceptance. In this stage, the individual comes to the point of no longer avoiding the inevitable result of the situation (the death, disaster, etc.). They begin to accept the outcome and its finality. The individual's attention is on planning and moving forward. The individual focused on the positives within their relationships and begins concentrate on the future (6).

Grief and Individuals with Intellectual and Developmental Disabilities

Current research has shown individuals with intellectual and/or developmental disabilities experience feelings of grief and loss just like everyone else. Uncertainties related to how an individual with I/DD comprehends death and loss limits the amount of information shared with them about these topics by their caregivers (3), (11).

They may not have a complete grasp on the concepts related to death, such as the finality of death in which every living creature dies, the causes of death, the certainty of one's own death, and after death there is no coming back to life. Misconceptions about death and dying can lead individuals with I/DD to misperceptions, increased confusion and complicated grief (3) (11).

Having open conversations with individuals allows them the chance to participate and express personal choices related to grief and loss. Sheltering individuals with I/DD is a lost opportunity for them to express their feelings and mourn those they care about (3). Communication difficulties have been cited as one of the main challenges for caregivers to discuss grief and loss with individual with I/DD (11).

For individuals with cognitive disabilities the loss of a close family member, staff members, and other caregivers, can cause them to question their own safety and security. These losses can affect all aspects of their daily routines due to their increased dependence on others for assistance (3). They may experience feelings of uneasiness due to changes in staff and fear of not knowing who will take care of them next, as individuals rarely have the opportunity to choose their own caregivers (3) (14).

Many individuals do not adapt well to change, so the sudden loss of a caregiver, family member or house mate might cause worry, frustration, and emotional outbursts. This may present in the form of increased behaviors, especially if the individual is autistic or non-verbal, and/or has a history of behavioral or mental health diagnoses (14).

Some individuals may be left with unanswered questions and may fear what the future holds for them if their loss has not been acknowledged or they have been left out of the grieving process (14).

It is important to maintain routines and consistency as much as possible, while allowing for an open and safe place to express grief. Oftentimes, some individuals with an I/DD may have no initial reaction, and/or don't express any sadness at all and resume normal activities. Delayed grief may be experienced at another stage of life, or another event reminds them of the event which triggers a grief reaction. For example, children who experience loss may not experience grief until adolescence or adulthood (10).

Pandemic - Related Grief

Many individuals have experienced varying degrees of grief due to the COVID-19 pandemic. This grief may be related to the loss of a loved one but may also be related to the loss of a job; an inability see friends or family members; missed special events (e.g. graduations, funerals, weddings, vacations); and changes to daily routines.

It is important to remember grief is a universal emotion; there is no right or wrong way to experience it, and the significance of a loss is determined by the person who experiences it. Individuals who survived COVID-19 may have feelings of guilt, especially if a family member or close friend did not survive. Fear and anxiety related to future hospitalizations due to near-death experiences may continue long-term (5).

Prolonged Grief Responses Due to the Pandemic

If multiple losses happen at the same time, grief can be prolonged and can delay a person's ability to adapt, heal, and recover. Prolonged grief can leave individuals, as well as staff, feeling both emotionally and physically exhausted.

As a result of the complicated circumstances of the pandemic, many people have experienced a prolonged grief response. Continuous media coverage of the pandemic continues to re-traumatize individuals who experienced loss. Individuals who recovered from COVID-19 may still suffer with fear and anxiety and require evaluation for post-traumatic stress disorder (PTSD) (4).

Some symptoms of a prolonged grief response may present as:

- An inability to be with a loved one when the end is near and/or at their death.
- An inability to attend a funeral, a memorial service or a wake.
- An inability to gather with friends and family to talk and share stories about the person who has passed.
- Withdrawal from friends and family in general.
- Withdrawal from activities they typically enjoy.

Persistent Complex Bereavement Disorder

For some individuals, feelings of grief and loss are totally overwhelming and don't improve over time. Persistent complex bereavement disorder is a DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, 5th ed.) diagnosis assigned to individuals who experience an unusually disabling or prolonged response to bereavement.

Persistent complex bereavement disorder causes sufferers to feel extreme yearning for a deceased loved one, usually over an extended period of time. Painful emotions are so long lasting and severe, individuals may have trouble resuming their own life. Feelings of grief are sometimes accompanied by destructive thoughts and behaviors, (which may include suicidal thoughts), as well as an inability to resume any semblance of their normal life. In worst case scenarios, it can leave individuals totally despondent (feeling profound hopelessness) (6).

Working through Grief

There are many activities, which can help individuals and caregivers cope with feelings of grief in a constructive way. Below are some activities to try:

- Coordinate a date and time for individuals and direct support staff to honor the deceased individual by reciting a selected poem, spiritual reading, or a prayer (2).
- Develop a virtual memory book, box, or webpage to remember a loved one, and ask individuals, family and friends to contribute their memories, stories or mementos. Assist those individuals who may not be able to participate in this activity by themselves (14) (2).
- Take part in an activity, such as planting a tree or preparing a favorite meal, which has significance for the individual and the loved one who died (2).

Asking for Help

- If an individual is experiencing a prolonged grief response, schedule an appointment with the individual's primary care physician (PCP) to discuss options for treatment and counseling. Seek out grief counseling or mental health services, support groups, or hotlines, especially those that can be offered over the phone or online (2).
- Seek spiritual support from faith-based organizations, including your religious leaders and congregations, if applicable (2).
- Seek support from other trusted community leaders and friends (2).



Develop Traditions and Rituals

- Consider implementing new rituals or traditions into the daily routine, to help replace those lost. Some ideas are:
 - Movie night.
 - Game night.
 - Ice cream sundae night.
 - Visiting a farmers market.
 - Going thrift shopping.
 - Playing a board game.
 - Playing music or sing songs.
 - Taking a walk or a hike together.
 - Having a group scavenger hunt (16).

Transitional Objects

- Encourage the use of symbols and “transitional” objects to help individuals express their grief. Some ideas to try:
- Create special bracelets with beads which spell the deceased person’s name or initials.
 - Materials can be purchased at most arts and crafts stores and are fairly inexpensive. You can also include beads which may reflect the deceased person’s hobbies or personality traits. A bead with a sun imprinted on it could represent someone with a sunny disposition, or a bead with a fish might represent someone who loved fishing. *(Please be aware, some individuals may not be able to wear these bracelets, due to the choking hazard they pose.)*



Traditional Mourning Armbands

- Buying black mourning armbands and writing the deceased person’s name on them with a silver or gold colored marker. (A dozen black mourning armbands can be purchased on Amazon or Walmart for around \$20.00.)



Other Arts and Crafts Projects

- Creative artistic expressions of grief can help individual's release their feelings and emotions in a non-judgmental and creative way. Encourage individuals to draw a picture of their lost loved one, paint a scene depicting their favorite memory of them, or create a collage of memories using small scenes from various individuals.

Goodbye Letter

- Helping an individual to write a goodbye letter can provide a therapeutic release of bottled-up sentiments, they may have been unable to express.
- It also gives individuals a chance to "talk to" their loved one and tell them all the things they were unable to say before they died. A letter also helps them say their final goodbyes in case of a sudden or accidental death (14).

Call the Family

- Help the individual call their friend's family and introduce themselves. Offering condolences is a nice way to break the ice and explain to the family what role you (or someone else), had in their loved one's life. The family may not be aware of the relationship and may not know where to begin in deciding who to include in the final arrangements (14).

Gather Pictures

- When someone is grieving the loss of a friend, old photos may bring joy and comfort. You can also help an individual to compile them in a photo album they can look at whenever they miss the individual.
- Sharing photos of the individual may help family members to see a different side of their family member than the one they knew. Perhaps it will give them insight into the personality of their family member that only others were allowed to see. Consider making duplicates of a special photo to give to others who may be grieving (16).

Playlist of Favorite Songs

- Music has a special way of healing the loss of someone. There are hundreds of songs written about loss and grief. Be sure to include any song, which may have special meaning to the individual. Sharing the playlist with the family can be a nice gesture. Some examples are below (8).
 - "You Have Been Loved" by George Michael.

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- "See You Again" by Carrie Underwood.
 - "I'll Be Missing You" by Puff Daddy ft. Faith Evans.
 - "Wake Me Up When September Ends" by Green Day.
 - "Everybody Hurts" by R.E.M.
 - "Who'd You Be Today" by Kenny Chesney.
 - "Hurt" by Christina Aguilera.
 - "There you'll be" by Faith Hill.
 - "Heaven Was Needing a Hero" by Jo Dee Messina.
 - "In The Arms of an Angel" by Sarah McLachlan.

Make a Memory Box

- Once the direct support staff has gathered up all of the items and returned everything the family is entitled to, you may want to ask the family if a special friend to the individual can have a special item which reminds them of their friend who has passed away. This does not have to be something of high monetary value. It can be something that holds a special memory of a time, place or even the two of them shared. Simple things like a used ticket from the movies, or a small souvenir of a trip, may comfort someone going through the grieving process (14).

Books about Grief and Loss

There are many books on the market which can help an individual to learn and deal with grief, death, loss, and mourning at any age. If the individual can read on their own, offer them a selection of books, or make a special trip to the local library or bookstore, so they can choose their own.

Allow individuals the freedom and flexibility of reading whenever they are ready to find out more information on the grief process. Never force anyone to participate in any activity they may not be ready for. Give individuals the opportunity to ask questions and find out more information whenever they are ready to learn more.

Resources for Grief and Loss

Printable downloads: <https://guide.peacefully.com/resources/worksheets-to-help-those-coping-with-grief>

How to deal with grief: <https://www.helpguide.org/articles/grief/coping-with-grief-and-loss.htm>

Creating a memorial: <https://onthewaytowhereyouregoing.com/honor-your-loved-one/>

100 ways to celebrate a life: <https://www.loveliveson.com/100-best-celebration-of-life-ideas-2/>

Tips for Survivors: Coping with Grief after a Disaster or Traumatic Event:
<https://store.samhsa.gov/sites/default/files/d7/priv/sma17-5035.pdf>

Tips for Health Care Practitioners and Responders: Helping survivors cope with grief after a disaster or traumatic event: <https://store.samhsa.gov/product/Tips-for-Health-Care-Practitioners-and-Responders-/SMA17-5036>

Helping Kids Grieve: <https://sesamestreetincommunities.org/topics/grief/>

Get Immediate Help in a Crisis

Sometimes fear and anxiety can be overwhelming and can cause strong emotions. If you or someone you care for needs help to recover from their grief and/or is having thoughts about hurting themselves or someone else, please call 911 or one of the following:

- **VA Copes Warm-line:** CALL OR TEXT: 877-349-MHAV | 877-349-6428
Monday–Friday: 9:00 a.m.–9:00 p.m., Saturday–Sunday: 5:00 p.m.–9:00 p.m.
- **Disaster Distress Helpline:** Call or text 1-800-985-5990 (press 2 for Spanish).
- **National Suicide Prevention Lifeline:** 1-800-273-TALK (8255) for English, 1-888-628-9454 for Spanish, or Lifeline Crisis Chat.
- **Veteran’s Crisis Line:** 1-800-273-TALK (8255) or Crisis Chat or text: 8388255.
- **The Trevor Project (Crisis Support for LGBTQ youth):**
<https://www.thetrevorproject.org/>: 1-866-488-7386 or Text START to 678-678

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