



# Grief & Loss

# Learning Objectives

Participants will be able to:

- Identify and use techniques to cope with loss related to caregiving.
- Understand loss related to terminal illness, chronic illness and death of a loved one.
- Discuss the meaning of grief and understand the grief process and normal grief responses
- Understand anticipatory grief.
- Identify maladaptive grief responses.
- Identify and use techniques to cope with grief and loss.

*We value your opinion. Please ask your instructor for an evaluation form at the close of this session.*

# Loss Related to Caregiving

- Some of the feelings you may experience include:
  - Guilt.
  - Sadness.
  - Anxiety.
  - Withdrawal.
  - Irritability.
  - Feeling overwhelmed.
  - Anger/frustration.
  - Feeling helpless.
  - Change in appetite.



# Steps For Coping

- Write feelings down:
  - Writing or journaling is not for everyone.
  - For individuals who enjoy writing, it can be a wonderful way to express feeling of loss and grief.
- Read a book on coping with grief:
  - There are several books available on the issues of caregiving, self-help, grieving and loss.
- Caregivers need to make time for themselves
  - For some individuals that may mean time spent with friends, family members or participating in a group.
  - Others may need time alone.
  - There are still others who need to spend time doing something active such as gardening or walking.

# Steps For Coping



- Get Help when needed:
  - Family and friends can provide some of the assistance for the family.
  - Counseling with professionals
  - The Internet is another resource for finding help nationally and in the community.
  - Community organizations are a great resource for various types of help.

# Loss Related To Terminal Illness

- Watching declining health makes dealing with terminal illness difficult.
- What is important to realize is that the family member is going to die, and that it is important to help make their passing as peaceful as possible.
- A terminally ill person is very aware that their declining health is leading them towards death.
- No matter how nonchalant they may appear to be, inside they are going through many emotions. It is up to the family to be a net of support.

# Loss Related To Terminal Illness

- Family members overwhelmed with their own grief can generate an atmosphere of gloom and depression.
- This makes the situation worse causing anger, apathy, and hopelessness within the family unit and the terminally ill person.
- The inevitable is going to happen. Focus on making the last days, months, or years pleasurable and spirited. Moreover, be natural.
  - Do not try to create a false environment of excessive seriousness or unnatural optimism. This will annoy the terminally ill person
  - Realizing that the family is doing so much to seemingly appease them can make the ill person even more depressed.

# Loss Related To Terminal Illness

- The best thing to do is to conduct life as normally as possible.
  - It is important to integrate the care needs of the ill family member in as natural a manner as possible.
  - If they are accustomed to cooking their own food and doing their own chores, allow them to continue if they are able. If they need assistance, then assist.
  - Telling them that they should lie down and rest is discouraging.
  - Unless they ask you to take over things they are accustomed to doing—don't.

# Loss Related To Terminal Illness

- Death is not an easy event to deal with or plan for.
- Emotions can be volatile and planning can be stressful.
- Realize that the terminally ill person may be reserved or spiteful as they near their end.
- Recognize that family is the greatest resource for the terminally ill.
- A concerted effort by all close to the ill is the only way to make their exit peaceful and without residual negativity.
- Planning during declining illness will make the aftermath of the death easier and allow for proper closure.

# Loss Related To Death Of A Loved One

- The death of a loved one can be the most stressful event in a person's life.
- A wide array of emotions can be experienced, such as sadness, anger, anxiety, guilt, and despair. Changes in sleep patterns and appetite can occur, as well as physical illness.
- These are all normal parts of grieving and the feelings can ebb and flow over time.
- Each person experiences grief in his or her own way
- It is very important to seek out people who understand your loss.
- It takes a long time to complete the grieving process

# When A Spouse Dies

- Millions of caretakers lose their spouses each year.
  - Because our society has few mourning rituals other than the memorial service, they may find themselves alone and disconsolate just when they are most in need of comfort.
- In similar fashion, adult children who lose a parent may find that their co-workers are too nervous about intruding to even acknowledge their loss.
  - Every year, almost 12 million adults lose a parent; it is the single most common cause of bereavement in the United States.

# When A Spouse Dies

- In a society that idolizes youth and turns away from aging and death, few of us understand grieving.
- We aren't educated to see that grief is a normal process that takes its own time.
- The bereaved may expect the sense of loss to subside quickly and automatically, and find it difficult to move forward when it does not.



# When A Parent Dies

- One of the most difficult issues is understanding our parent's grief, especially when we too are grieving.
- It's been six months since Dad died. When will Mom stop crying?
  - The death of a spouse is one of life's most stressful events. While there is no timeline to grieving, most believe it takes 2-4 years to adjust one's life to the death of a spouse.
- "Dad was so decisive before. Now he can hardly make a decision." "Mom thinks she's destitute even though she's financially all right." "Why?"
  - Overwhelming fear, forgetfulness, indecisiveness, anger, and guilt are all normal reactions to loss.

# When A Parent Dies

- One of our prime identities in life is as someone's wife or husband.
- Creating a new "you" by establishing a new self-identity, purpose for life, and new goals is frightening, takes time and is hard work.
- Over time and with work, tears will lessen and only appear at times that hold special memories.
- “My parents' wedding anniversary is coming soon. What should I do?”
  - Acknowledge the anniversary. Talk about it. Take your cue from your parent on how to observe the day.

# When A Parent Dies

- Secondary Losses.

- When a loved one dies, many other losses are involved depending on the roles they played in the family.
- These losses may receive little recognition but can be very frightening to the survivor since they represent new challenges to be faced and new skills to be learned.

- “What about me? I've lost a loved one too.”

- Take care of and be good to yourself. Allow yourself to express your feelings.
- Don't feel you have to shelter your parent or your children from your tears and pain. Children learn by observing and one way to teach them and others that it is all right to grieve is to cry and grieve in front of them. By showing them your pain, you allow them to express theirs.

# When A Sibling Dies

- Each family member has his/her own special history and the shared bonds that become a part of that history.
- When a sibling dies, the bonds are shattered and the history has a void that cannot be filled.
- There will be memories of growing up in the family that can no longer be shared. As Barbara Rosof says in her book, *The Worst Loss: How Families Heal from the Death of a Child*:

“Today’s families are smaller; many children have only one sibling. For such children to lose their sibling makes them an only child, a sole survivor. The child they grew up with, who lived through their childhood with them, their witness, is gone.”

# When A Sibling Dies

- New family roles may emerge.
  - A surviving sibling may have to replace a brother or sister as the caregiver for elderly parents
  - Another may be named as the guardian for surviving nieces or nephews.
- Fulfilling these new roles can also cause adult siblings to put off dealing with their own pain and loss.
- Another aspect of the void may find the survivor feeling abandoned by the sibling whose role has always been that of the dependable ally in times of crisis.

# When A Sibling Dies

- There will be times when adult siblings have not remained close.
  - Such a bereaved sibling may feel remorse or even guilt, because they have grown estranged.
  - Siblings may be ambivalent about their relationships in life but in death the power of their bond becomes clear.
  - These are understandable feelings that will be part of the grieving process.
- If the surviving sibling is married and the spouse has not experienced this loss, it may introduce stress into the relationship.
  - The spouse may be bewildered and even unsympathetic that this loss is causing so much sorrow in their own family.
  - Spouses may need to be told how they can be supportive.

# When A Sibling Dies

- Finding Support

- Many siblings find it is helpful to talk to others about their brother or sister.
- Often, simply finding another bereaved sibling with whom to share concerns and feelings provides a path to healing.
- Adult siblings may be living in areas where no one knew their deceased brother or sister. In this case, it may be helpful to seek out and communicate with people who did know their sibling.
- It is important to remember that the relationship between siblings is potentially the longest of their lives.
- The death of an adult sibling at any age is a significant loss.

# Loss Related To Chronic Illness

- Living with a chronic illness has a profound impact on one's life and creates grief in response to the losses it causes in our lives.
- A chronically ill person is likely to endure multiple losses that may include the loss of control and personal power, as well as loss of independence, loss of identity, loss of financial status and loss of one's customary lifestyle.
- The chronically ill person may also have to face the possible relinquishing of their hopes and dreams and the fear of more ongoing losses.
- Changing roles in family, work and social situations also can create adjustment problems for everyone involved.

# Loss Related To Chronic Illness

- Family members and partners are likely to be experiencing the same feelings, along with their own feelings about how the illness is impacting their life.
- If these issues are not worked out, relationships may fall apart.
- Often most difficult is the loss of the identity one held before becoming sick.
- It can be difficult to feel good about oneself as illness or disability is incorporated into a new self-image.
- It is not surprising that many people facing these multiple losses experience high levels of anger, fear, helplessness, hopelessness, resentment, depression and damaged self-esteem.

# Grief Explored

- Grief is a pattern of responses a person experiences after a loss of a valued person, object, belief, or relationship.
- Loss leads to mourning - the period of time during which the grief is expressed, and resolution and integration of the loss occurs.
- Bereavement is the period of grief following the death of a loved one.
- Grief is a natural process, a universal experience which makes us human.
- The loss of a spouse, child or parent affects our very identities and also can result in a sudden change in circumstances leading to fear of not knowing what lies ahead.

# Grief Explored

- The death of someone close can be a life-changing experience.
  - If you are the primary caregiver of someone you love, this experience can affect every aspect of your life for some time.
  - It is natural to grieve the death of a loved one before, during and after the actual time of their passing.
- Everyone experiences grief as an individual and the impact of grief depends upon the individual's past experiences with loss, their culture, their coping skills, belief system, faith and life experiences.

# Understanding The Grief Process

- Reactions to death cover a wide and confusing range of emotions.
- Experts try to list "the stages of grief," or "the tasks of mourning," so we can better understand the process. But there is no real order to the grieving process.
- Grief does not proceed in an orderly fashion any more than life itself does.
- Immediate response following the death is probably shock, numbness, and a sense of disbelief.
- From the outside, we may look to others as if we're holding up well. In fact, the reality of the death has not yet penetrated our awareness.

# Understanding The Grief Process

- In the months after the funeral, however, this numbness turns to intense feelings of separation, pain, and yearning.
- After a time, despair may set in. Many feel extremely depressed, have trouble concentrating, and act very disorganized and forgetful.
- Strong feelings of guilt may surface.
- It may be impossible to avoid acting irritable, anxious, or restless.
- Feelings may swing from one pole to another – at one time wanting to avoid all reminders of the deceased person and at other times wanting to reminisce and recall the past.
- It is all about learning to live with the reality of the loss.

# Normal Grief Response To Loss

- Grief differs based on who we are, whom we have lost, and how much our day-to-day life is altered by the death.
- Grief is unique in its impact, course and meaning to each of us.
- Experiencing the loss of a partner, a parent or sibling, or a lifelong friend, with whom we share history, often have special meaning to us.
- We tend to think only of the emotional reactions to loss. Yet, people also experience physical and behavioral reactions.
- The intensity of grief changes over time and through personal growth.

# Anticipatory Grief

When someone has a prolonged fatal illness, suffers from serious progressive memory impairment, or is being kept alive by extreme medical interventions, friends and family members may begin grieving the loss of their loved one's former self long before the actual death.

This pre-death mourning is often referred to as anticipatory grief.



# Anticipatory Grief

- Anticipatory grief can provoke a wide range of intense and often conflicting feelings.
- It is not unusual to experience guilt or shame for wishing it were finally over, or feeling as though their loved one is already a memory instead of a still-living presence.
- They may agonize over what they should or shouldn't do regarding medical interventions and wish for a quick and final resolution that will relieve them of the painful burden of decision making.
- Other commonly experienced reactions include hopefulness quickly countered by hopelessness, rage, denial, extreme anxiety, and deep depression.
- Throughout the time of anticipatory grief, it is crucial to seek and accept as much caring support as possible.

# Maladaptive Grief

- When individuals fail to grieve they may experience complicated mourning. Symptoms of complicated mourning include:
  - The person cannot speak of the deceased at all without experiencing intense and fresh grief.
  - Relatively minor events may trigger an intense grief reaction.
- The person who has sustained the loss is unwilling to move material possessions belonging to the deceased.
- The person who has sustained the loss may develop symptoms similar to those the deceased experienced before death. They may be convinced they have the same disease even after tests are negative.

# Maladaptive Grief

- The person withdraws from friends and family or makes a radical change in their lifestyle.
- The person has a compulsion to imitate the dead person, particularly if he or she had no conscious desire nor competence for the same behavior.
- The individual behaves in reckless or self-destructive ways.
- The person develops a phobia about illness or death.
- The individual avoids any reminder of the deceased.

Complicated grief may come as a result of the inability to express grief or from unresolved grief from an earlier death of a loved one.

# Coping With Loss & Grief

- Experiencing loss and grief is a painful process. It may be the most demanding challenge we will face on our journey.
- Loss is an inescapable part of the human experience. None of us will get through life without having multiple losses.
  - Many will be minor and some will be profound.
  - The impact of each will vary according to how significant it is to us, but all will carry a degree of grief.
- Remember that coming to terms with loss is a very personal and private journey, but it is not one that should be traveled alone. Just as we need strength from inside, we need support from outside.

# The Aspen Tree ©



- We chose the aspen tree to represent family caregivers and older adults who need care
- Aspen trees appear to be individuals. In reality, they are one organism sharing the same far-reaching root system. These interconnected roots give the aspen resilience, strength and beauty, often in the harsh conditions of winter at high elevations.
- Like aspen trees, family caregivers, their aging family members, health and human service providers, and the community are all connected.

Just because you care does not mean you have to care alone.

Written by: Romie Myers, R.N., and Zanda Hilger, M. Ed., LPC, Family Caregiver Education, Area Agency on Aging, Revised by Zanda Hilger and Betty Purkey, revised April, 2017 Permission is granted to duplicate any and all parts of this program to use in education programs supporting family members caring for elders.

This program is one module of a comprehensive caregiver education program.

Go to [www.familycaregiversonline.net](http://www.familycaregiversonline.net) for more information about this and

- Other training programs
- Internet links
- Frequently asked caregiver questions
- Legal forms
- Phone numbers
- Fact sheets
- And more

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