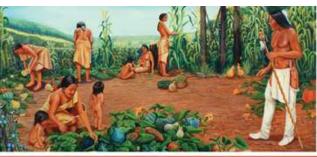
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# American Cancer Society Circle Of Life™ Cancer Education and Wellness for American Indian and Alaska Native Communities

Wellness along the Cancer Journey: Nearing the End Of Life

**Revised October 2015** 

Chapter 8: Coping with the Death of a Loved One

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# Coping with the Death of a Loved One

Group Discussion				
	True	False	Not Sure	
1. There is only one phase of grief.				
2. There are many emotions that occur during the phases of grief.				

When a person loses someone important to them, they go through a normal process called grieving. Grieving is natural and should be expected. Over time, it can allow the person to accept and understand their loss.

Bereavement is what a person goes through when someone close to them dies. It is the state of having suffered a loss. The person who has lost someone is said to be bereaved.

Mourning is the outward expression of loss and grief. Mourning includes rituals and other actions that are specific to each person's culture, personality, and religion. Bereavement and mourning are both part of the grieving process.

Grieving involves feeling many different emotions over time, all of which help the person come to terms with the loss of a loved one. But keep in mind that grief doesn't look the same for everyone. And, every loss is different.

# **Grief is a process**

Many people think of grief as a single instance or very short period of pain or sadness in response to a loss – like the tears shed at a loved one's funeral. But grieving is the entire emotional process of coping with a loss, and can last a long time. Normal grieving allows us to let a loved one go and keep on living in a healthy way.

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Grieving is painful, but it is important that those who have suffered a loss be allowed to express their grief, and that they be supported throughout the process. Each person will grieve for a loved one in a different way. The length and intensity of the emotions people go through will also vary from person to person.

Although grief is described as happening in phases or stages, it doesn't often feel like that to the bereaved person. It may feel more like a roller coaster, with ups and downs that make it hard to see that any progress is being made in dealing with the loss. It is normal for people to feel better for a while, only to become sad again. Sometimes, people wonder how long the grieving process will last for them, and when they can expect some relief. There is no one answer to this question, but some of the factors that affect the intensity and length of grieving are:

- The kind of relationship the person had with the one who died
- The circumstances of the death
- The grieving person's own life experiences

Researchers have studied emotional states that people may go through while grieving. The first feelings usually include shock or numbness. Then, as the person sees how their life is affected by the loss, emotions start to surface. The early disbelief is often replaced by emotional upheaval, which can involve anger, loneliness, disbelief, or denial. These feelings can come and go over a long period of time. The final phase of grief is the one in which people find ways to come to terms with and accept the loss.

## Shock, Numbness, and Disbelief

Often, a person's first reaction to a loss is one of shock, disbelief, and numbness. This can last anywhere from a few hours to days or weeks. During this time, the bereaved person may feel emotionally "shut off" from the world. Still, the numbness may be disturbed by pangs of distress, which are often triggered by reminders of the deceased. The person may feel agitated or weak, cry, engage in aimless activities, or be preoccupied with thoughts or images of the person they lost.

The rituals of mourning – receiving friends, preparing for the funeral, and burial – often structure this time for people. They are seldom left alone. Sometimes the Nearing the End of Life Rev-10.8.15

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sense of numbness lasts through these activities, leaving the person feeling as though they are just "going through the motions" of these rituals.

## Painful Emotions Come when Facing the Loss

At some point the reality of the loss starts to sink in, and the numbness wears off. This is sometimes called confrontation – when the feelings of loss are most intense and painful. This is the time that the person starts to face the loss and starts to cope with the changes this loss has caused in their life.

People have many different ways of dealing with loss, so there may be many different, equally intense emotions. During this time, grief tends to come in waves of distress. The person may seem disorganized. They may have trouble thinking and remembering, and doing day-to-day activities. This can last for weeks to months. Some or all of the following may be seen in a person who is grieving – the person may:

- Withdraw socially
- Have trouble thinking and concentrating
- Become restless and anxious at times
- Not feel like eating
- Look sad
- Feel depressed
- Dream of the deceased (or even have hallucinations or "visions" in which the person briefly hears or sees the deceased)
- Lose weight
- Have trouble sleeping
- Feel tired or weak
- Become preoccupied with death or events surrounding death
- Search for reasons for the loss (sometimes with results that make no sense to others)
- Dwell on mistakes, real or imagined, that they made with the deceased

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- Feel somehow guilty for the loss
- Feel all alone and distant from others
- Express anger or envy at seeing others with their loved ones

It is often during this time that a grieving person needs the most emotional support. Finding support can be the key to a person's eventual recovery and acceptance of the loss. Family members, friends, support groups, community organizations, or mental health professionals (therapists or counselors) can all help during this time.

## Accepting the Loss and Learning to Live without the Loved One

By this time, people have begun to recognize what the loss means to them in day-to-day life. They have felt the pain of grief. Usually, the person comes to accept the loss slowly over the months that follow it. This acceptance includes adjusting to daily life without the deceased.

Like the earlier parts of the process, acceptance does not happen overnight. It's common for it to take as long as a year or more for someone to resolve the emotional and life changes that come with the death of a loved one. The pain may become less intense, but it is normal to feel emotionally involved with the deceased for many years after their death. In time, the person should be able to reclaim the emotional energy that was invested in the relationship with the deceased, and use it in other relationships.

# Grieving Can Go on for Many Years

Adjusting to the loss does not mean that all the pain is over for those who were very close to the deceased. Grieving for a loved one includes losing the future someone expected with that person. This must also be mourned. The sense of loss can last for decades. For example, years after a parent dies, the bereaved may be reminded of the parent's absence at an event they would have been expected to attend. This can bring back strong emotions, and may call for mourning yet another part of the loss.

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# **Grief Can Take Unexpected Forms**

Emotions are different when the relationship was difficult. A person who had a difficult relationship with the deceased (a parent who was abusive, estranged, or abandoned the family, for example) is often surprised after their death because the emotions are so painful. It's not uncommon to have profound distress as the bereaved mourns the relationship they had wished for with the person who died, and lets go of any chance of achieving it. Others might feel relief, while some wonder why they feel nothing at all on the death of such a person. Regret and guilt are common, too. This is all part of the process of adjusting and letting go.

# Grief Can Be Different If the Loss Comes after a Long Illness

The grief experience may be different when the loss occurs after a long illness rather than suddenly. When someone is terminally ill, their loved ones often start to grieve before the death because they know that the loss is going to happen. This is called "anticipatory grief," and it is a normal response. It can help people complete unfinished business and prepare the person for the actual loss, but it might not lessen the pain they feel when the person dies.

Usually, the period just before the person's death is a time of physical and emotional preparation for those close to them. At this stage, loved ones may feel the urge to withdraw emotionally from the person who is ill.

Many people think they are prepared for the loss because death is expected. But when their loved one actually dies, it can still be a shock and bring about unexpected feelings of sadness and loss. For most people, the actual death starts the normal grieving process.

# **Major Depression and Complicated Grief**

It is common for people to have sadness, pain, anger, bouts of crying, and a depressed mood after a loved one dies. It is important to know about the normal grief responses and when the situation might be worsening into clinical depression.

About one in five bereaved people will develop major depression (also called clinical depression). This can often be helped by therapy and medicines. People at

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highest risk for clinical depression include those who have been depressed before, those with no support system, those who have had problems with alcohol or drug abuse, or those who have other major life stresses.

Symptoms of major depression not explained by normal bereavement may include:

- Constant thoughts of being worthless or hopeless
- Ongoing thoughts of death or suicide (other than thoughts that they would be better off dead or should have died with their loved one)
- Being unable to perform day-to-day activities
- Intense guilt over things done or not done at the time of the loved one's death
- Delusions (beliefs that are not true)
- Hallucinations hearing voices or seeing things that are not there), except for "visions" in which the person briefly hears or sees the deceased
- Slower body responses and reactions
- Extreme weight loss

If symptoms such as these last for more than two months after the loss, the bereaved person may benefit from getting professional help. If the person tries to hurt themselves, or plans to do so, they need help right away.

In some people, the grieving process can go on for a long time. This happens more commonly in those who were very close to the deceased. It is most often caused by attempts to deny or get away from the pain or to avoid letting go.

If normal mourning does not occur, or if the mourning goes on for a long time without any progress, it is called "complicated grief" or "unresolved grief." Symptoms of this might include:

- Continued disbelief in the death of the loved one, or emotional numbness over the loss
- Being unable to accept the death

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- Feeling preoccupied with the loved one or how they died
- Intense sorrow and emotional pain, sometimes including bitterness or anger
- Being unable to enjoy good memories about the loved one
- Blaming oneself for the death
- Wishing to die to be with the loved one
- Excessively avoiding reminders of their loss
- Continuous yearning and longing for the deceased
- Feeling alone, detached from others, or distrustful of others since the death
- Trouble pursuing interests or planning for the future after the death of the loved one
- Feeling that life is meaningless or empty without the loved one
- Loss of identity or purpose in life, feeling like part of themselves died with the loved one

For some people who are taking care of a loved one with a long-term illness, complicated grief can actually start while their loved one is still alive. Caregivers under severe stress, especially if the outlook is bleak, may be at higher risk of having abnormal grief even before the death.

If someone has any of the above symptoms of major depression or complicated grief, discuss it with a qualified health or mental health professional. Treatment is important, since people with complicated grief are at risk of their emotional illness getting worse, and are at higher risk of committing suicide.

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# **Coping with Loss**

Ideally, the bereaved person will work through the process of grieving. With time and support, they will accept and make sense of the loss, experience the pain, and adapt to a new life and identity.

If someone has lost a loved one, the following suggestions may help them cope with the loss:

- Feel the pain and all the other emotions, too. It does not work for a person to tell themselves how to feel or let others tell them how they should feel.
- Be patient with the process. A person should not feel pressure from their own or others' expectations. Accept that each person needs to experience their pain, their emotions, and their own way of healing – all in their own time. Don't judge a person's emotions or compare them to others. No one can tell a person how they should mourn or when to stop.
- A person needs to be able to recognize their feelings and cry when needed. This is needed for healing.
- Get support. A person needs to talk about their loss, their memories, and their experience of the life and death of a loved one. Some people think they are protecting their family and friends by not expressing their sadness. They should remember that they can ask others for what they need. For instance, they can find and talk to others who have lost a loved one.
- Try to maintain a normal lifestyle. A person should avoid major life changes (for example, moving, changing jobs, changing important relationships) within the first year of bereavement. This helps allow a person to keep their roots and some sense of security.
- They should take care of themselves, for example, by eating well and exercising. Physical activity helps to release tension. They can also allow themselves small physical pleasures, like warm baths, naps, and favorite foods, to help renew themselves.
- They should avoid drinking too much alcohol or using other drugs. This can harm the body as well as dull the emotions. It is likely to slow recovery and may cause new problems.

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- A person will need to forgive themselves for all the things they said or didn't say or do. Compassion and forgiveness for oneself and others are important in healing.
- Take a break from grief. Although everyone must work through grief, people
  do not need to focus on it all the time. It is healthy to find distractions like
  going to a movie, dinner, or a ball game; reading a good book; listening to
  music; or getting a massage or manicure.
- Prepare for holidays and anniversaries knowing that strong feelings may come back. Decide whether to keep certain family traditions or create new ones. Plan in advance how to spend time and with whom. Do something to honor the memory of the loved one.
- Join a bereavement support group. Other people can encourage, guide, and offer comfort. They can also offer practical ideas and information, and help a person feel less alone. If there is not a nearby support group, online groups may be helpful.
- When a person feels ready, they can do something creative. Some options include:
  - o Write a letter to the person who died.
  - Start keeping a journal.
  - o Make a scrapbook.
  - o Paint pictures.
  - o Plant flowers or trees.
  - Become involved in a cause or activity that the deceased person loved.

Appendix E has some other ideas for coping with the loss of a loved one. It may be helpful to copy this page and put it somewhere to review it from time to time.

# **Family Changes**

When a loved one dies, it affects all their family members and loved ones. Each family finds its own ways of coping with death. A family's attitudes and reactions

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are shaped by cultural and spiritual values, as well as by the relationships among family members. It will take time for a bereaved family to regain its balance.

The ability of each member to grieve with one another is important in helping the family cope. Each person will experience the loss differently and have different needs. As hard as it may be, it is important for family members to remain open and honest when talking with each other. This is not the time for family members to hide their emotions to try and protect one another.

The loss of one person in a family means that roles in the family will change. Family members will need to talk about the effects of this change and the shift in responsibilities. This time of change is stressful for everyone. It is important to be even more gentle and patient with each other.

# **Getting Professional Help for the Grieving Process**

Bereavement counseling is a special type of professional help. A person may be able to find it through hospice services or from a health care provider. This type of counseling has been shown to reduce the level of distress that mourners go through after the death of their loved one. It can help them move more easily through their grief. Bereavement counseling can also help them adjust to their new lives without the deceased.

# **Helping Someone Who Is Grieving**

It is common to feel awkward when trying to comfort someone who is grieving. Many people do not know what to say or do. Use the following suggestions as a guide.

# What to Say

- Acknowledge the situation. Example: "I heard that your\_\_\_\_\_ died." Use the word "died." This shows a person is more open to talk about how the other person really feels.
- Express concern. Example: "I'm sorry to hear that this happened to you."
- Communicate genuinely and don't hide feelings. Example: "I"m not sure what to say, but I want you to know I care."

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- Offer support. Example: "Tell me what I can do for you."
- Ask how the bereaved person feels. Don't assume how they will feel on any given day.

#### What to Do

- Be there. Even if a person does not know what to say, just having someone near can be very comforting.
- Listen and give support. But don't try to force someone if they are not ready to talk.
- Be a good listener. Accept whatever feelings the person expresses. Even if you can't imagine feeling like they do, never tell them how they should or shouldn't feel.
- Give reassurance without minimizing the loss. Try to have empathy with the person without assuming to know how they feel.
- Offer to help with errands, shopping, housework, cooking, driving, or yard work. Sometimes people want help and sometimes they don't. Even if they don't accept the offer of help, they're not rejecting a person or their friendship.
- Avoid telling the person "You're so strong." This puts pressure on the person to hold in feelings and keep acting "strong."
- Continue to offer support even after the first shock wears off. Recovery takes a long time.
- It may help to check in with the bereaved on anniversaries of the death, marriage, and birthday of the deceased, since those can be especially difficult.

If a grieving person begins to abuse alcohol or drugs, neglects personal hygiene, develops physical problems, or talks about suicide, it may be a sign of complicated grief or depression. Someone close to them will want to suggest they think about getting professional help.

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If there are signs they may be thinking about suicide, do not leave them alone. Try to get the person to get help from their health care provider or the nearest hospital emergency room right away. If that is not possible, call 911. If it is safe to do so, remove firearms and other tools for suicide.

# **Grief during Childhood**

It is a very common myth that children cannot understand death. How old a child is at the time of the death is important because a child's understanding of death changes with age. Preschool children usually think death is short term and reversible. Between the ages of 5 and 9, they understand that the person is gone, but see it more as a separation. After about ages 9 or 10, they begin to understand that death is final.

Children grieve. They just don't have all the ways to cope that adults do. They often have feelings like sadness, anger, guilt, insecurity, and anxiety, even though they might need help naming these feelings. Children sometimes show anger toward surviving family members. They may start having behavior or discipline problems. They may think the death is their fault, especially if they had once "wished" the person dead or were ever angry at the person. Or they may start having nightmares or acting younger than their age. Sometimes they may seem unaffected by the loss and then express their feelings about the death at unexpected moments.

# Talking with Children about Death

It's hard to comfort others when a person is deep in their own grief. Parents may not want to discuss death with their children because they don't want to upset them. Or they may not want to worsen their own pain. But talking with them about death will help the children deal with their fears.

Children's responses to death are often very different from those of adults. Sometimes a child's feelings or questions about death may seem inappropriate or upsetting. But it is important to recognize that they are also trying to understand and accept what has happened. A parent can help them by listening and showing interest in what they have to say.

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Answer whatever questions they may have as openly and honestly as possible. Telling children that someone "went away" or is "sleeping" can lead to confusion and fear. If a small child knows that sickness caused the death, it is important to explain that only serious sicknesses cause death. With small children, it may be helpful to talk about dead flowers, insects, or birds, as a way to explain death.

A parent may want to use the following suggestions when talking to a child about death:

- Explain what happened in a way they can understand. Children know when a person is hiding something, so be open and honest.
- Assure the child that this is not their fault; they didn't cause the death.
- Encourage them to talk. Listen and accept their feelings no matter how hard it may be.
- Answer their questions in brief and simple terms. Telling them they are too young to understand only avoids dealing with the problem and may upset them even more. It is OK to not have all the answers.
- Reassure them that they will still be loved and taken care of. Tell them
  where they can expect to live and who will be taking care of them if they
  have lost a parent.
- Show affection, support, and consistency. Let the child know that someone will be there to help as much as possible. Be sure they have people in their lives they can count on.
- Share feelings using words they will understand and in a way that won't be overwhelming. For example, it is OK to let the child know the parent is hurting, too. If a parent tries to hide their feelings, the child may think they shouldn't share theirs.

Years ago, people believed that children should not be included in funerals, because it would be too hard for them, they were too young to understand, or they would be frightened by other people's distress. Since then, it has been learned that this is not true. Children have later said they often felt betrayed when they could not say good-bye to someone they loved. They felt that their

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relationship with the person who died was not valued; that death was not a natural part of life, but instead something too frightening to confront; and that they were emotionally not able to cope.

Attending the funeral helps children understand that death is final. Explain to them that a funeral is the way we say good-bye to the people we love. Depending on their age, attention span, and how much adult supervision they need, children may take part in all of the ritual or only some of it.

If children will be at the funeral, they should be prepared for what they will see and hear. Someone should take them aside and tell them enough detail so they will know what to expect. If there will be a viewing with an open casket, the child needs to know that. Depending on how young they are, it might be useful to talk about what it means to be dead. Explain that people will come to the funeral home to visit with the family and offer their sympathy. Also explain any other routines or rituals that will be followed. If there is a religious service, describe what will happen there. Tell them if there will be a trip to a cemetery where the casket will be placed in the ground and covered up. They should know that they may see people cry, and that it is OK. They will see the normal expressions of how people feel when they lose someone important to them. Seeing this gives the child permission to express their emotions.

Whatever social ritual may happen afterward should also be explained. Children sometimes have a hard time understanding what looks like a party after services where people looked pretty sad. Explain that people can't be sad all the time and there will be other times when the sadness will come back. Children also should expect that the sadness we feel when someone has died can last a while, but eases as time goes on.

Children will generally want to take part in this ritual with their family. If they seem frightened by what they imagine a funeral to be, they probably have a false impression or misunderstanding about it. It is a rare child who does not want to take part in something that the whole family is doing, but if they don't, gently ask the child what they think will happen and what they are worried about. For example, the child may not fully understand the transition from life to death and worry that the person is still alive when they are put into the ground. Remind

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them again what being dead means and that the person as they knew them is no longer here.

## Losing a Child

Facing the death of a child is likely the hardest thing a parent ever has to do. People who have lost a child have stronger grief reactions. They often have more anger, guilt, physical symptoms, greater depression, and a loss of meaning and purpose in life. A loss is tragic at any age, but the sense of unfairness of a life unfulfilled magnifies the anger and rage felt by parents.

A longer and slower bereavement and recovery should be expected when someone loses a child. The grief may get worse with time, as the parents see others going through the milestones they expected to pass with their child.

Bereaved parents may especially be helped by a grief support group. A group may be available in the local community. A parent can ask their child's cancer care team for referral to counseling or local groups.

They can also contact Compassionate Friends, a nationwide self-help organization offering support to families who have experienced the death of a child, of any age, from any cause. It publishes a newsletter and other materials on parent and sibling bereavement. Compassionate Friends also refers people to nearly 600 local chapters. Online support groups, such as those at GriefNet, can be another way to connect with others.

# **Activity**

Spotting <u>depression</u> as soon as possible can stop a downward spiral of sadness and inability to function. Many successful ways of treating depression are now available to help people regain joy, hope, and the ability to cope.

Below are some of the signs and symptoms of depression.

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Symptom	Yes	No
You feel sad or "empty" almost every day for most of the		
day.		
Your days bring little or no pleasure.		
You are either too restless or slowed down most of the time.		
You have trouble making decisions or have problems		
concentrating.		
You have lost interest in eating, or you are overeating. You		
have gained or lost weight without dieting.		
You have trouble sleeping, wake up early, or find yourself		
oversleeping.		
You feel many aches and pains that don't go away.		
You have lost interest in sex.		
You cry often.		
You feel tired or a lack of energy almost every day.		
You have thought about hurting yourself or attempted		
suicide.		

It isn't unusual for caregivers to have a couple of these symptoms for a short time. However, they may mean that they are at risk for becoming depressed.

If someone has symptoms that last for two weeks or longer, or their symptoms are severe enough to interfere with normal day-to-day life, see a health care provider or mental health professional to be checked for depression. It may be helpful to print this checklist and take it to show a health care provider or health care team.

Looking at the last question, if you or someone you know longs to die, they may be seriously depressed. See a health care provider right away.

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# **Story of Hope**

"Indian people generally, don't deal well with death. We don't take lightly losing someone that we love. We hold that death with us for a long time. When it comes to the point of examining your own mortality, that's a real difficult task. Because then you have to ask yourself questions of I don't want to deal with not being here. I love life. That's where I am at. I can't imagine not being here. But there's no guarantee that, you know, tomorrow I won't be here because of some other intervening cause that I have no control over. But right now, you know, Creator knows that I am not ready. He knows all the reasons, but whether or not that's within my control, I don't know. So examining mortality, I think is a real healthy thing to do for Indian people and for cancer survivors, in particular. I know that a lot of people that are Indian that have cancer and that have survived have a real difficult time finding other people to talk to about mortality. And we need to do that. We need to slay the dragon. Because if we are really being true to our cultural beliefs and our spirituality, then there's no fear. Because we are being taken care of. It doesn't matter."

Bonnie "Heavy Runner" Craig, Blackfeet Ovarian Cancer Survivor
 (Clark, R., (Producer) & Craig, B. (Artist). (2007). Survivor Video Vignettes: Perceptions of Death.
 [Web]. Retrieved from http://www.natamcancer.org/vignettes/bc2-palliative.html)

## **Key Messages**

- After the death of a loved one, family and friends need to take care of themselves, allow themselves to feel their emotions, be in touch with supportive friends and family, and focus on staying healthy.
- If someone keeps having sadness and anger, they should talk to a health care provider. Many times these feelings will fade, but other times they develop into depression, which can be treated.
- After the death of a loved one, family and friends are normally able to ease back into a new daily routine over time. It may take time to gain back energy and strength.