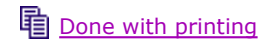


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Supportive Care: Loss, Grief and Bereavement

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Introduction

This patient summary on loss, grief, and bereavement is adapted from the summary written for health professionals by cancer experts. This and other credible information about cancer treatment, screening, prevention, supportive care, and ongoing clinical trials, is available from the National Cancer Institute. The passage from the final stage of cancer to the death of a loved one is different for everyone. This summary describes loss, grief, and bereavement, the stages of grief, and methods for coping with grief. This summary also includes sections on children and grief.

Overview

People cope with the loss of a loved one in many ways. For some, the experience may lead to personal growth, even though it is a difficult and trying time. There is no right way of coping with death. The way a person grieves depends on the personality of that person and the relationship with the person who has died. How a person copes with grief is affected by the experience with cancer, the way the disease progressed, the person's cultural and religious background, coping skills, mental history, support systems, and the person's social and financial status.

The terms bereavement, grief, and mourning are often used in place of each other, but they have different meanings. Bereavement is the state of having suffered a loss and experiencing many emotions and changes. The time spent in a period of bereavement depends on how attached the person was to the person who died, and how much time was spent anticipating the loss.

Grief is the normal process of reacting to the loss. Grief reactions may be felt in response to physical losses (for example, a death) or in response to symbolic or social losses (for example, divorce or loss of a job). Each type of loss means the person has had something taken away. As a family goes through a cancer illness, many losses are experienced, and each triggers its own grief reaction. Grief may be experienced as a mental, physical, social, or emotional reaction. Mental reactions can include anger, guilt, anxiety, sadness, and despair. Physical reactions can include sleeping problems, changes in appetite, physical problems, or illness. Social reactions can include feelings about taking care of others in the family, seeing family or friends, or returning to work. As with bereavement, grief processes depend on the relationship with the person who died, the situation surrounding the death, and the person's attachment to the person who died. Grief may be described as the presence of physical problems, constant thoughts of the person who died, guilt, hostility, and a change in the way one normally acts.

Mourning consists of the conscious, unconscious, and cultural reactions to loss. Mourning includes the process of incorporating the experience of loss into ongoing life. Mourning is also influenced by cultural customs, rituals, and society's rules for coping with loss.

"Grief work" includes the processes that a mourner needs to complete before resuming daily life. These processes include separating from the person who died, readjusting to a world without him or her, and forming new relationships. To separate from the person who died, a person must find another way to redirect the emotional energy that was given to the loved one. This does not mean the person was not loved or should be forgotten, but that the mourner needs to turn to others for emotional satisfaction. The mourner's roles, identity, and skills may need to change to readjust to living in a world without the person who died. The mourner must give other people or activities the emotional energy that was once given to the person who died in order to redirect emotional energy.

People who are grieving often feel extremely tired because the process of grieving usually requires physical and emotional energy. The grief they are feeling is not just for the person who died, but also for the unfulfilled wishes and plans for the relationship with the person. Death often reminds people of

past losses or separations. Mourning may be described as having three phases, including the urge to bring back the person who died, disorganization and sadness, and reorganization.

Phases of a Life-Threatening Illness

Understanding how other people cope with a life-threatening illness may help the patient and his or her family prepare to cope with their own illness. A life-threatening illness may be described as having four phases, including the phase before the diagnosis, the acute phase, the chronic phase, and recovery or death.

The phase before the diagnosis of a life-threatening illness is the period of time just before the diagnosis when a person realizes that he or she may develop an illness. This phase is not usually a single moment, but extends throughout the period when the person has a physical examination, including various tests, and ends when the person is told of the diagnosis.

The acute phase occurs at the time of the diagnosis when a person is forced to understand the diagnosis and make decisions about his or her medical care.

The chronic phase is the period of time between the diagnosis and the result of treatment. It is the period of time when a patient tries to cope with the demands of life while also undergoing treatment and coping with the side effects of treatment. In the past, the period between a cancer diagnosis and death usually lasted only a few months, and this time was usually spent in the hospital. Today, people can live for years after being diagnosed with cancer.

In the recovery phase, people cope with the mental, social, physical, religious, and financial effects of cancer.

The final (terminal) phase of a life-threatening illness occurs when death is likely. The focus then changes from curing the illness or prolonging life, to providing comfort and relief from pain. Religious concerns are often the focus during this time.

End-of-Life Decisions

Caring for a person with cancer starts after symptoms begin and the diagnosis is made and continues until the patient is in remission, is cured, or has died. End-of-life decisions should be made early after the diagnosis, before there is a need for them. These issues are not pleasant or easy to think about. They usually reflect a person's philosophical, moral, religious, or spiritual background. If a person has certain feelings about end-of-life issues, they should be made known so that they can be carried out. However, since these are sensitive issues, they are frequently not discussed by patients, families, or doctors. People often feel that there will be plenty of time to talk later about the issues. Many times, though, when the end-of-life decisions are necessary, the patient and family are not able to make the decisions, and the decisions are made by people who may not know the patient's wishes.

As a first step in making decisions for the end of life, patients should complete a Health Care Proxy (HCP) form. These forms are not the same in

each state, but they have the same purpose. The HCP allows the patient to identify a person (called a proxy) to make medical decisions if the patient becomes unable to do so. The form may not need to be notarized, but it must be witnessed by two other people. In some states, the HCP is better than a living will because the patient does not have to say exactly which decisions need to be made, but that the proxy knows "what I would want."

A living will is similar to the HCP. It allows a person to state in more detail what his or her feelings are about medical care, nutrition, and other medical issues so that doctors and caregivers can carry out these wishes. Living wills are not available or legal in all states. Living wills usually require a lawyer and notarization to be complete in states where they are recognized.

Do Not Resuscitate (DNR) orders tell doctors and other health care givers that a patient does not want extreme measures to be taken to save his or her life. The patient will not be resuscitated if his or her heart stops or if he or she stops breathing. People who do not want extreme measures taken should talk with their doctor and other caregivers and complete forms as early as possible (for example, when they are admitted to the hospital) instead of waiting until they cannot make this decision. Although people with end-stage disease and their families are usually uncomfortable talking about these issues, doctors and nurses may gently and respectfully bring up the issues when the time is right.

Programs like hospice are now available that allow patients to die at home. Some states have DNR forms available for people wishing to die at home which protects them from being resuscitated. These advanced directive forms are signed by the patient's doctor and express the patient's wishes and intent not to be resuscitated. These issues are important to discuss wherever a patient is being cared for, whether at home, in the hospital, at hospice, in a nursing home, or elsewhere.

The Pathway to Death

People who are dying may move towards death over longer or shorter periods of time and in different ways. Different causes of death result in different paths toward death.

The pathway to death may be long and slow, sometimes lasting years, or it may be a rapid fall towards death (for example, after a car accident) when the chronic phase of the illness, if it exists at all, is short. The "peaks and valleys" pathway describes the patient who repeatedly gets better and then worse again (for example, a patient with AIDS or leukemia). Another pathway to death may be described as a long, slow period of failing health and then a period of stable health (for example, patients whose health gets worse and then stabilizes at a new, more limiting level). Patients on this pathway must readjust to losses in functioning ability.

Deaths from cancer often occur over a long period of time, and may involve long-term pain and suffering, and/or loss of control over one's body or mind. Deaths caused by cancer are likely to drain patients and families physically and emotionally because they occur over a long period of time.

Anticipatory Grief

Anticipatory grief is the normal mourning that occurs when a patient or family is expecting a death. Anticipatory grief has many of the same symptoms as those experienced after a death has occurred.

Anticipatory grief includes depression, extreme concern for the dying person, preparing for the death, and adjusting to changes caused by the death. Anticipatory grief gives the family more time to slowly get used to the reality of the loss. People are able to complete "unfinished business" with the dying person (for example, saying "good-bye," "I love you," or "I forgive you").

Anticipatory grief may not always occur. Anticipatory grief does not mean that before the death, a person feels the same kind of grief as the grief felt after a death. There is not a set amount of grief that a person will feel. The grief experienced before a death does not make the grief after the death last a shorter amount of time.

Grief that follows an unplanned death is different from anticipatory grief. Unplanned loss may overwhelm the coping abilities of a person, making normal functioning impossible. Mourners may not be able to realize the total impact of their loss. Even though the person recognizes that the loss occurred, he or she may not be able to accept the loss mentally and emotionally. Following an unexpected death, the mourner may feel that the world no longer has order and does not make sense.

Some people believe that anticipatory grief is rare. To accept a loved one's death while he or she is still alive may leave the mourner feeling that the dying patient has been abandoned. Expecting the loss often makes the attachment to the dying person stronger. Although anticipatory grief may help the family, the dying person may experience too much grief, causing the patient to become withdrawn.

Phases of Grief

The process of bereavement may be described as having four phases:

1. Shock and numbness: Family members find it difficult to believe the death; they feel stunned and numb.
2. Yearning and searching: Survivors experience separation anxiety and cannot accept the reality of the loss. They try to find and bring back the lost person and feel ongoing frustration and disappointment when this is not possible.
3. Disorganization and despair: Family members feel depressed and find it difficult to plan for the future. They are easily distracted and have difficulty concentrating and focusing.
4. Reorganization

Treatment

Grief counseling helps mourners with uncomplicated grief go through the phases of grief. Grief counseling can be provided by professionally trained people, or in self-help groups where bereaved people help other bereaved people. All of these services may be available in individual or group settings.

The goals of grief counseling include:

- helping the bereaved to accept the loss by helping him or her to talk about the loss
- helping the bereaved to identify and express feelings related to the loss (for example, anger, guilt, anxiety, helplessness, and sadness)
- helping the bereaved to live without the person who died and to make decisions alone
- helping the bereaved to separate emotionally from the person who died and to begin new relationships
- providing support and time to focus on grieving at important times such as birthdays and anniversaries
- describing normal grieving and the differences in grieving among individuals
- providing continuous support
- helping the bereaved to understand his or her methods of coping
- identifying coping problems the bereaved may have and making recommendations for professional grief therapy

Grief therapy is used with people who have complicated grief reactions. The goal of grief therapy is to identify and solve problems the mourner may have in separating from the person who died. When separation difficulties occur, they may appear as physical or behavior problems, delayed or extreme mourning, conflicted or extended grief, or unexpected mourning (although this is seldom present with cancer deaths).

Grief therapy may be available as individual or group therapy. A contract is set up with the individual that establishes the time limit of the therapy, the fees, the goals, and the focus of the therapy.

In grief therapy, the mourner talks about the deceased and tries to recognize whether he or she is experiencing an expected amount of emotion about the death. Grief therapy may allow the mourner to see that anger, guilt, or other negative or uncomfortable feelings can exist at the same time as more positive feelings about the person who died.

Human beings tend to make strong bonds of affection or attachment with others. When these bonds are broken, as in death, a strong emotional reaction occurs. After a loss occurs, a person must accomplish certain tasks to complete the process of grief. These basic tasks of mourning include accepting that the loss happened, living with and feeling the physical and emotional pain of grief, adjusting to life without the loved one, and emotionally separating from the loved one and going on with life without him or her. It is important that these tasks are completed before mourning can end.

In grief therapy, six tasks may be used to help a mourner work through grief: 1) develop the ability to experience, express, and adjust to painful grief-related changes, 2) find effective ways to cope with painful changes, 3) establish a continuing relationship with the person who died, 4) stay healthy and keep functioning, 5) reestablish relationships and understand that others may have difficulty empathizing with the grief they experience, and 6) develop a healthy image of oneself and the world.

Complications in grief may come about due to uncompleted grief from earlier losses. The grief for these earlier losses must be managed in order to handle

the current grief. Grief therapy includes dealing with the blockages to the mourning process, identifying unfinished business with the deceased, and identifying other losses that result from the death. The bereaved is helped to see that the loss is final and to picture life after the grief period.

Complicated Grief

Complicated grief reactions require more complex therapies than uncomplicated grief reactions. Adjustment disorders (especially depressed and anxious mood or disturbed emotions and behavior), major depression, substance abuse, and even post-traumatic stress disorder are some of the common problems of complicated bereavement. Complicated grief is identified by the extended length of time of the symptoms, the interference caused by the symptoms, or by the intensity of the symptoms (for example, intense suicidal thoughts or acts).

Complicated or unresolved grief may appear as a complete absence of grief and mourning, an ongoing inability to experience normal grief reactions, delayed grief, conflicted grief, or chronic grief. Factors that contribute to the chance that one may experience complicated grief include the suddenness of the death, the gender of the person in mourning, and the relationship to the deceased (for example, an intense, extremely close, or very contradictory relationship). Grief reactions that turn into major depression should be treated with both drug and psychological therapy. One who avoids any reminders of the person who died, who constantly thinks or dreams about the person who died, and who gets scared and panics easily at any reminders of the person who died may be suffering from post-traumatic stress disorder. Substance abuse may occur, frequently in an attempt to avoid painful feelings about the loss and symptoms (such as sleeplessness), and can also be treated with drugs and psychological therapy.

Children and Grief

In the past, children were thought to be miniature adults and were expected to behave as adults. It is now understood that there are differences in the ways in which children and adults mourn.

Unlike adults, bereaved children do not experience continual and intense emotional and behavioral grief reactions. Children may seem to show grief only occasionally and briefly, but in reality a child's grief usually lasts longer than that of an adult. Mourning in children may need to be addressed again and again as the child gets older. As the surviving child grows, he or she will think about the loss repeatedly, especially during important times in his or her life, such as going to camp, graduating from school, getting married, or giving birth to his or her own children. This longer period of grief is due to the fact that the child's ability to experience intense emotions is limited.

A child's grief may be influenced by his or her age, personality, stage of development, earlier experiences with death, and his or her relationship with the deceased. The surroundings, cause of death, family members' ability to communicate with one another and to continue as a family after the death can also affect grief. The child's ongoing need for care, the child's opportunity to share his or her feelings and memories, the parent's ability to cope with stress, and the child's steady relationships with other adults are also other

factors that may influence grief.

Children do not react to loss in the same ways as adults. Grieving children may not show their feelings as openly as adults. Grieving children may not withdraw and dwell on the person who died, but instead may throw themselves into activities (for example, they may be sad one minute and playful the next). Often families think the child "doesn't really understand" or has "gotten over" the death. Neither is true; children's minds protect them from what is too powerful for them to handle. Children's grieving periods are shortened because they can not think through their thoughts and feelings like adults. Also, children have trouble putting their feelings about grief into words. Instead, his or her behavior "speaks" for the child. Strong feelings of anger and fears of abandonment or death may show up in the behavior of grieving children. Children often play death games as a way of working out their feelings and anxieties. These games are familiar to the children and provide safe opportunities to express their feelings.

Children's Grief and Developmental Stages

Children at different stages of development have different understandings of death and the events near death.

Infants

Infants do not recognize death, but feelings of loss and separation are part of developing an awareness of death. Children who have been separated from their mother may be sluggish, quiet, unresponsive to a smile or a coo, undergo physical changes (for example, weight loss), be less active, and sleep less.

Age 2-3 years

Children at this age often confuse death with sleep and may experience anxiety as early as age 3. They may stop talking and appear to feel overall distress.

Age 3-6 years

At this age children see death as a kind of sleep; the person is alive, but only in a limited way. The child cannot fully separate death from life. Children may think that the person is still living, even though he or she might have been buried, and ask questions about the deceased (for example, how does the deceased eat, go to the toilet, breathe, or play?). Young children know that death occurs physically, but think it is temporary, reversible, and not final. The child's concept of death may involve magical thinking. For example, the child may think that his or her thoughts can cause another person to become sick or die. Grieving children under 5 may have trouble eating, sleeping, and controlling bladder and bowel functions.

Age 6-9 years

Children at this age are commonly very curious about death, and may ask questions about what happens to one's body when it dies. Death is thought of as a person or spirit separate from the person who was alive, such as a skeleton, ghost, angel of death, or "bogey man." They may see death as final and frightening but as something that happens mostly to old people (and not to themselves). Grieving children can become afraid of school, have learning problems, develop antisocial or aggressive behaviors, become overly

concerned about their own health (for example, developing symptoms of imaginary illness), or withdraw from others. Or, children this age can become too attached and clinging. Boys usually become more aggressive and destructive (for example, acting out in school), instead of openly showing their sadness. Children may feel abandoned by both their deceased parent and their surviving parent because the surviving parent is grieving and is unable to emotionally support the child.

Ages 9 and older

By the time a child is 9 years old, death is known to be unavoidable and is not seen as a punishment. By the time a child is 12 years old, death is seen as final and something that happens to everyone.

In American society, many grieving adults withdraw and do not talk to others. Children, however, often talk to the people around them (even strangers) to see the reactions of others and to get clues for their own responses. Children may ask confusing questions. For example, a child may ask "I know grandpa died, but when will he come home?" This is a way of testing reality and making sure the story of the death has not changed.

Other Issues for Grieving Children

Children's grief expresses three issues: (1) Did I cause the death to happen? (2) Is it going to happen to me? (3) Who is going to take care of me?

Did I cause the death to happen?

Children often think that they have magical powers. If a mother says in irritation, "You'll be the death of me" and later dies, her child may wonder if he or she actually caused the mother's death. Also, when children argue, one may say (or think), "I wish you were dead." Should that child die, the surviving child may think that his or her thoughts actually caused the death.

Is it going to happen to me?

The death of another child may be especially hard for a child. If the child thinks that the death may have been prevented (by either a parent or a doctor) the child may think that he or she could also die.

Who is going to take care of me?

Since children depend on parents and other adults to take care of them, a grieving child may wonder who will care for him or her after the death of an important person.

Grieving Children: Treatment

A child's grieving process may be made easier by being open and honest with the child about death, using direct language, and incorporating the child into memorial ceremonies for the person who died.

Explanation of death

Not talking about death (which indicates that the subject is off limits) does not help children learn to cope with loss. When discussing death with children, explanations should be simple and direct. Each child should be told the truth using as much detail as he or she is able to understand. The child's questions should be answered honestly and directly. Children need to be reassured

about their own security (they often worry that they will also die, or that their surviving parent will go away). Children's questions should be answered, making sure that the child understands the answers.

Correct language

A discussion about death should include the proper words, such as "cancer," "died," and "death." Substitute words or phrases (for example, "passed away," "he is sleeping," or "we lost him") should never be used because they can confuse children and lead to misunderstandings.

Planning memorial ceremonies

When a death occurs, children can and should be included in the planning and participation of memorial ceremonies. These events help children (and adults) remember loved ones. Children should not be forced to be involved in these ceremonies, but they should be encouraged to take part in those portions of the events with which they feel most comfortable. If the child wants to attend the funeral, wake, or memorial service, he or she should be given in advance a full explanation of what to expect. The surviving parent may be too involved in his or her own grief to give their child full attention, therefore, it may be helpful to have a familiar adult or family member care for the grieving child.

References and Resources for Grieving Children

There are many helpful books and videos that can be shared with grieving children.

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Culture and Response to Grief and Mourning

Grief felt for the loss of a loved one, the loss of a treasured possession, or a loss associated with an important life change, occurs across all ages and

cultures. However, the role that cultural heritage plays in an individual's experience of grief and mourning is not well understood. Attitudes, beliefs, and practices regarding death must be described according to myths and mysteries surrounding death within different cultures.

Individual, personal experiences of grief are similar in different cultures. This is true even though different cultures have different mourning ceremonies, traditions, and behaviors to express grief. Helping families cope with the death of a loved one includes showing respect for the family's cultural heritage and encouraging them to decide how to honor the death. Important questions that should be asked of people who are dealing with the loss of a loved one include:

1. What are the cultural rituals for coping with dying, the deceased person's body, the final arrangements for the body, and honoring the death?
2. What are the family's beliefs about what happens after death?
3. What does the family feel is a normal expression of grief and the acceptance of the loss?
4. What does the family consider to be the roles of each family member in handling the death?
5. Are certain types of death less acceptable (for example, suicide), or are certain types of death especially hard to handle for that culture (for example, the death of a child)?

Death, grief, and mourning spare no one and are normal life events. All cultures have developed ways to cope with death. Interfering with these practices may interfere with the necessary grieving processes. Understanding different cultures' response to death can help physicians recognize the grieving process in patients of other cultures.

To Learn More

For more information, call the National Cancer Institute's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237); TTY at 1-800-332-8615. The call is free and a trained information specialist is available to answer your questions.

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