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Table of Contents

Clinical Trials

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**Cancer Statistics** 

**Research & Funding** News

About NCI



bereavement, mourning, and grieSEARCH

Last Modified: 08/31/2010

**Page Options** Print This Document E-Mail This Document Bookmark & Share **Quick Links** 

Director's Page Dictionary of Cancer Terms NCI Drug Dictionary **Funding Opportunities** NCI Publications Advisory Boards and Groups Science Serving People Español

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LiveHelp online chat



# **NCI Highlights**

NCI Issues Cancer Trends Progress Report: 2009/2010 Update

The Nation's Investment in Cancer Research FY 2011

Report to the Nation Finds Continued Declines in Cancer Rates

Table of Contents
Overview
Definitions of Terms
Grief
Bereavement
Mourning
Types of Grief Reactions
Anticipatory Grief
Normal or Common Grief
Stage Models of Normal Grief
Patterns of Complicated Grief
Prolonged or Complicated Grief as a Mental Disorder
Risk Factors for Complicated Grief and Other Negative Bereavement Outcomes
Situational: Expected or Unexpected Death
Personal: Personality Characteristics
Personal: Religious Beliefs
Personal: Gender
Personal: Age
Interpersonal Context: Social Support
Treatment
Normal or Common Grief Reactions
Psychosocial Treatment of Complicated Grief
Pharmacologic Treatment of Bereavement-related Depression
Children and Grief
Grief and Developmental Stages
Infants
Ages 2 to 3 years
Ages 3 to 6 years
Ages 6 to 9 years
Ages 9 years and older
Issues for grieving children
Interventions for Grieving Children
Explanation of death
Correct language
Planning rituals
References and resources for grieving children
Cross-cultural Responses to Grief and Mourning
Current Clinical Trials
Get More Information From NCI
Changes to This Summary (08/31/2010)
Questions or Comments About This Summary
More Information
About This PDQ Summary

# Overview

Health care providers will encounter bereaved individuals throughout their personal and professional lives.[1] The progression from the final stages of cancer to the death of a loved one is experienced in different ways by different individuals. Every person is unique, and thus there will be many individual differences in grief experiences. Most people will experience common or normal grief and will cope well; others will experience more severe grief reactions such as prolonged or complicated grief and will benefit from treatment. Some may even find that the cancer experience, although it is difficult and trying, may lead to significant personal growth.

Coping with death is usually not an easy process and cannot be dealt with in a cookbook fashion. The way in which a person will grieve depends on the personality of the grieving individual and his or her relationship with the person who died. The cancer experience; the manner of disease progression; one's cultural and religious beliefs, coping skills, and psychiatric history; the availability of support systems; and one's socioeconomic status all affect how a person will cope with the loss of a loved one via cancer.

This summary first defines the constructs of grief, bereavement, and mourning. It then distinguishes the grief reactions of anticipatory grief, normal or common grief, stage models of normal grief, and complicated or prolonged grief. Psychosocial and pharmacologic treatments are explained. The important developmental issues of children and grief are presented, and a section on cross-cultural responses to grief and mourning concludes the summary.

The following information combines theoretical and empirical reviews of the general literature on grief, bereavement, and mourning [<u>2-5</u>] and is not specific to loss via cancer. Where available, studies that have focused on cancer are emphasized.

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#### Back to Top

# **Definitions of Terms**

### Grief

Grief is defined as the primarily emotional/affective process of reacting to the loss of a loved one through death.[1] The focus is on the internal, intrapsychic process of the individual. Normal or common grief reactions may include components such as the following:[2]

- Numbness and disbelief.
- · Anxiety from the distress of separation.
- A process of mourning often accompanied by symptoms of depression.
- Eventual recovery.

Grief reactions can also be viewed as abnormal, traumatic, pathologic, or complicated. Although no consensus has been reached, diagnostic criteria for complicated grief have been proposed.[<u>3</u>] (Refer to the <u>Prolonged or Complicated Grief as a Mental Disorder</u> section of this summary for more information.)

#### Bereavement

Bereavement is defined as the objective situation one faces after having lost an important person via death.[1] Bereavement is conceptualized as the broadest of the three terms and a statement of the objective reality of a situation of loss via death.

# Mourning

Mourning is defined as the public display of grief.[1] While grief focuses more on the internal or intrapsychic experience of loss, mourning emphasizes the external or public expressions of grief. Consequently, mourning is influenced by one's beliefs, religious practices, and cultural context.

There is obvious overlap between grief and mourning, with each influencing the other; it is often difficult to distinguish between the two. One's public expression (i.e., mourning) of the emotional distress over the loss of a loved one (i.e., grief) is influenced by culturally determined beliefs, mores, and values.

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### Back to Top

# **Types of Grief Reactions**

Many authors have proposed types of grief reactions.[<u>1,2</u>] Research has focused on normal and complicated grief while specifying types of complicated grief [<u>3</u>] and available empirical support [<u>4</u>] with a focus on the characteristics of different types of dysfunction.[<u>1</u>] Controversy over whether it is most accurate to think of grief as progressing in sequential stages (i.e., stage theories) continues.[<u>5,6</u>] Most literature attempts to distinguish between normal grief and various forms of complicated grief such as chronic grief or absent/delayed/inhibited grief.[<u>1,3,4</u>]

Bereavement research has tried to identify these patterns by reviewing available empirical support [1] while also looking for evidence that these grief reactions are unique and not simply forms of major depression, anxiety, or post-traumatic stress.[7]

# **Anticipatory Grief**

Anticipatory grief refers to a grief reaction that occurs in anticipation of an impending loss.[8] Anticipatory grief is the subject of considerable concern and controversy.[9]

The term *anticipatory grief* is most often used when discussing the families of dying persons, although dying individuals themselves can experience anticipatory grief. Anticipatory grief includes many of the same symptoms of grief after a loss. Anticipatory grief has been defined as "the total set of cognitive, affective, cultural, and social reactions to expected death felt by the patient and family."[10]

The following aspects of anticipatory grief have been identified among survivors:

- Depression.
- Heightened concern for the dying person.
- Rehearsal of the death.
- Attempts to adjust to the consequences of the death.

Anticipatory grief provides family members with time to gradually absorb the reality of the loss. Individuals are able to complete unfinished business with the dying person (e.g., saying "good-bye," "I love you," or "I forgive you").

Anticipatory grief cannot be assumed to be present merely because a warning of a life-threatening illness has been given or because a sufficient length of time has elapsed from the onset of illness until actual death. A major misconception is that anticipatory grief is merely conventional (postdeath) grief begun earlier. Another fallacy is that there is a fixed volume of grief to be experienced, implying that the amount of grief experienced in anticipation of the loss will decrease the remaining grief that will need to be experienced after the death.[9]

Several studies [<u>11,12</u>] have provided clinical data documenting that grief following an unanticipated death differs from anticipatory grief. Unanticipated loss overwhelms the adaptive capacities of the individual, seriously compromising his or her functioning to the point that uncomplicated recovery cannot be expected. Because the adaptive capacities are severely assaulted in unanticipated grief, mourners are often unable to grasp the full implications of their loss. Despite intellectual recognition of the death, there is difficulty in the psychologic and emotional acceptance of the loss, which may continue to seem inexplicable. The world seems to be without order, and like the loss, does not make sense.

Some researchers report that anticipatory grief rarely occurs. They support this observation by noting that the periods of acceptance and recovery usually observed early in the grieving process are rarely found before the patient's actual death, no matter how early the forewarning.[9] In addition, they note that grief implies that there has been a loss; to accept a loved one's death while he or she is still alive can leave the bereaved vulnerable to self-accusation for having partially abandoned the dying patient. Finally, anticipation of loss frequently intensifies attachment to the person.

Although anticipatory grief may be therapeutic for families and other caregivers, there is concern that the dying person may experience too much grief, thus creating social withdrawal and detachment. Research indicates that widows usually remain involved with their dying husbands until the time of death.[13] This suggests that it was dysfunctional for the widows to have begun grieving in advance of their husbands' deaths. The widows could begin to mourn only after the actual death took place.

# Normal or Common Grief

In general, normal or common grief reactions are marked by a gradual movement toward an acceptance of the loss and, although daily functioning can be very difficult, managing to continue with basic daily activities. Normal grief usually includes some common emotional reactions that include emotional numbness, shock, disbelief, and/or denial often occurring immediately after the death, particularly if the death is unexpected. Much emotional distress is focused on the anxiety of separation from the loved one, which often results in yearning, searching, preoccupation with the loved one, and frequent intrusive images of death.[2]

Such distress can be accompanied by crying; sighing; having dreams, illusions, and even hallucinations of the deceased; and seeking out things or places associated with the deceased individual. Some bereaved people will experience anger, will protest the reality of the loss, and will have significant periods of sadness, despair, insomnia, anorexia, fatigue, guilt, loss of interest, and disorganization in daily routine.[2]

Many bereaved persons will experience highly intense, time-limited periods (e.g., 20–30 minutes) of distress, variously called grief bursts or pangs. Sometimes these pangs are understandable reactions to reminders of the deceased person, and at other times they seem to occur unexpectedly.[2]

Over time, most bereaved people will experience symptoms less frequently, with briefer duration, or with less intensity. Although there is no clear agreement on any specific time period needed for recovery, most bereaved persons experiencing normal grief will note a lessening of symptoms at anywhere from 6 months through 2 years postloss. Normal or common grief appears to occur in 50% to 85% of persons following a loss, is time-limited, begins soon after a loss, and largely resolves within the first year or two.

# Stage Models of Normal Grief

A number of theoretically derived stage models of normal grief have been proposed.[14-17] Most models hypothesize a normal grief process differentiated from various types of complicated grief. Some models have organized the variety of grief-related symptoms into phases or stages, suggesting that grief is a process marked by a series of phases, with each phase consisting of predominant characteristics. One well-known stage model,[18] focusing on the responses of terminally ill patients to awareness of their own deaths, identified the stages of denial, anger, bargaining, depression, and acceptance. Although widely used, this model has received little empirical support.

A more recent stage model of normal grief [2] organizes psychological responses into four stages: numbness-disbelief, separation distress, depression-mourning, and recovery.[5] Although presented as a stage model, this model explains "it is important to emphasize that the idea that grief unfolds inexorably in regular phases is an oversimplification of the highly complex personal waxing and waning of the emotional process."[2] Bereavement researchers have found empirical support for this four-stage model,[5] although other researchers have questioned these findings.[19,20]

# Patterns of Complicated Grief

Since the time of Sigmund Freud, many authors have proposed various patterns of pathologic or complicated grief.[<u>1,2</u>] Some proposed patterns come from extensive clinical observation [<u>20</u>] supported by various theories (e.g., psychodynamic defense mechanisms and personality traits associated with patterns of attachment).[<u>21</u>]

These patterns are described in comparison to normal grief and highlight variations from the normal pattern. They include descriptive labels such as the following:

- Inhibited or absent grief: A pattern in which persons show little evidence of the expected separation distress, seeking, yearning, or other characteristics of normal grief.
- Delayed grief: A pattern in which symptoms of distress, seeking, yearning, etc., occur at a much later time than is typical.
- Chronic grief: A pattern emphasizing prolonged duration of grief symptoms.
- Distorted grief: A pattern characterized by extremely intense or atypical symptoms.

Empirical reviews have not found evidence of inhibited, absent, or delayed grief and instead emphasize the possibility that these patterns are better explained as forms of human resilience and strength.[6] Evidence supports the existence of a minimal grief reaction—a pattern in which persons experience no, or only a few, signs of overt distress or disruption in functioning. This minimal reaction is thought to occur in

15% to 50% of persons during the first year or two after a loss.[6]

Empirical support also exists for chronic grief, a pattern of responding in which persons experience symptoms of common grief but do so for a much longer time than the typical year or two. Chronic grief is thought to occur in about 15% of bereaved persons.[6] It may look very much like major depression, generalized anxiety, and possibly post-traumatic stress.

In addition to these theoretical and empirically supported patterns of grief reactions, much emphasis has been placed on distinguishing normal grief from complicated grief. Most clinicians will be focused on understanding the differences between normal and complicated grief reactions: What is the difference? Under what circumstances should I refer a patient/family member for grief therapy?

# Prolonged or Complicated Grief as a Mental Disorder

The Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) includes bereavement as a diagnosable code to be used when bereavement is a focus of clinical attention following the death of a loved one. In current form it does not consist of formal diagnostic criteria and is generally considered a normal reaction to loss via death. In an attempt to clearly distinguish between normal grief and complicated grief, a consensus conference [22] has developed diagnostic criteria for a mental disorder referred to as prolonged grief disorder, proposing that it be included in the next revision of the DSM.[23]

Following are the proposed diagnostic criteria for complicated grief:[24]

- Criterion A: Person has experienced the death of a significant other, and response involves three of the four following symptoms, experienced at least daily or to a marked degree:
  - Intrusive thoughts about the deceased.
  - Yearning for the deceased.
  - Searching for the deceased.
  - Excessive loneliness since the death.
- Criterion B: In response to the death, four of the eight following symptoms are experienced at least daily or to a marked degree:
  - Purposelessness or feelings of futility about the future.
  - Subjective sense of numbness, detachment, or absence of emotional responsiveness.
  - Difficulty acknowledging the death (e.g., disbelief).
  - Feeling that life is empty or meaningless.
  - Feeling that part of oneself has died.
  - Shattered worldview (e.g., lost sense of security, trust, control).
  - Assumption of symptoms or harmful behaviors of, or related to, the deceased person.
  - Excessive irritability, bitterness, or anger related to the death.
- Criterion C: The disturbance (symptoms listed) must endure for at least 6 months.
- Criterion D: The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

These criteria have not been formally adopted, and thus there is no formal diagnostic category for prolonged grief disorders in the DSM. However, these criteria help in specifying symptoms, the severity of symptoms, and how to distinguish complicated grief from normal grief. Not all health care professionals agree that the duration of "at least 6 months" is the most accurate number, suggesting that the time period may be too short and that 6 months to 2 years may be more accurate.[25]

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#### Back to Top

# **Risk Factors for Complicated Grief and Other Negative Bereavement Outcomes**

One study [1] of 248 caregivers of terminally ill cancer patients investigated the presence of predeath

complicated grief and its correlates. Results revealed the following variables associated with higher levels of predeath complicated grief:

- Age younger than 60 years.
- Lack of perceived available social support.
- History of depression and current depression.
- Lower income.
- · Pessimistic thinking.
- Severity of stressful life events.

Of these correlates, pessimistic thinking and severity of stressful life events were independent predictors of predeath complicated grief.

Other research has focused on predictors of outcomes such as symptoms of depression and overall negative health consequences. Three categories of variables have been investigated:

- Situational (e.g., circumstances of the death).
- Personal (e.g., personality characteristics, gender).
- Interpersonal context (e.g., social support, kinship).

Most research has focused on spousal/partner loss and is not uniquely focused on death via cancer.

## Situational: Expected or Unexpected Death

Although theory suggests that a sudden, unexpected loss should lead to more difficult grief, empirical findings have been mixed.[2] The impact of an unexpected loss seems to be moderated by self-esteem and perceived control: Bereaved persons with low self-esteem and/or a sense that life is uncontrollable seem to suffer more depression and somatic complaints after an unexpected death than do bereaved persons with higher self-esteem and/or a sense of control.[2]

## Personal: Personality Characteristics

Attachment theory [3] has suggested that the nature of one's earliest attachments (typically with parents) predicts how one would react to loss. Bereaved persons with secure attachment styles would be least likely to experience complicated grief, while those with either insecure styles or anxious-ambivalent styles would be most likely to experience negative outcomes.[4]

In a study of 59 caregivers of terminally ill spouses, the nature of their attachment styles and marital quality were evaluated. Results showed that caregivers with insecure attachment styles or in marriages that were "security-increasing" were more likely to experience symptoms of complicated grief.[5] Persons with a tendency toward "ruminative coping," a pattern of excessively focusing on one's symptoms of distress, have also been shown to experience extended depression after a loss.[6]

## Personal: Religious Beliefs

Theory has proposed that strong religious beliefs and participation in religious activities could provide a buffer to the distress of loss, via two different mechanisms:

- A belief system that helps one cope with death.
- A network of social support that comes with religious participation.

However, empirical results about the benefits of religion in coping with death tend to be mixed, some showing positive benefit and others showing no benefit or even greater distress among the religious.[7] Studies that show a positive benefit of religion tend to measure religious participation as regular church attendance and find that the benefit of participation tends to be associated with an increased level of social support. Thus it appears that religious participation via regular church attendance and the resulting increase in social support may be the mechanisms by which religion is associated with positive grief outcomes.

# Personal: Gender

In general, men experience more negative consequences than women do after losing a spouse. Mortality rates of bereaved men and women are higher for both men and women compared to nonbereaved people; however, the relative increase in mortality is higher for men than for women. Men also tend to experience greater degrees of depression and greater degrees of overall negative health consequences than do women after a spouse's death.[2] Some researchers have suggested that the mechanism for this difference is the lower level of social support provided to bereaved men than that provided to bereaved women.

## Personal: Age

In general, younger bereaved persons experience more difficulties after a loss than do older bereaved

persons. These difficulties include more severe health consequences, grief symptoms, and psychological and physical symptoms.[2] The reason for this age-related difference may be the fact that younger bereaved persons are more likely to have experienced unexpected and sudden loss. However, it is also thought that younger bereaved persons may experience more difficulties during the initial period after the loss but may recover more quickly because they have more access to various types of resources (e.g., social support) than do older bereaved persons.[2]

# **Interpersonal Context: Social Support**

Social support is a highly complex construct, consisting of a variety of components (perceived availability, social networks, supportive climate/environment, support seeking) and measured in a variety of ways. However, as mentioned above, lack of social support is a risk factor for negative bereavement outcomes: It is both a general risk factor for negative health outcomes and a bereavement-specific risk factor for negative outcomes after loss.[2] For example, after the death of a close family member (e.g., spouse), many persons report a number of related losses (often unanticipated) such as the loss of income, lifestyle, and daily routine—all important aspects of social support.

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- Back to Top

# Treatment

The following information concerns treatment of grief after the death of a loved one, not necessarily death as a result of cancer.

# Normal or Common Grief Reactions

Some controversy continues about whether normal or common grief reactions require any intervention by medical or mental health professionals. Researchers disagree about whether credible evidence on the efficacy of grief counseling exists.[<u>1-4</u>] Most bereaved persons experience painful and often very distressing emotional, physical, and social reactions; however, most researchers agree that most bereaved persons adapt over time, typically within the first 6 months to 2 years. Thus, the question is whether it is wise to devote professional time to interventions for normal grief when resources are limited and the need for accountability is great.

One approach is to use a spectrum of interventions, from prevention to treatment to long-term maintenance care. [5] In this model, preventive interventions could be one of the following:

- Universal and targeted to all persons in the population.
- · Selective and targeted to persons with known risk factors.
- Indicated for persons experiencing significant symptom distress.

In contrast, formal treatment of bereaved persons would be reserved for those identified as experiencing complicated or pathologic grief reactions. Finally, longer-term maintenance care may be warranted for persons experiencing chronic grief reactions.

Another approach has focused on families.[<u>6</u>,<u>7</u>] This brief, time-limited approach (four to eight 90-minute sessions over 9 to 18 months) identifies families at increased risk for poor outcomes and intervenes, with emphasis on improving family cohesion, communication, and conflict resolution. Adaptive coping, with efforts to strengthen family solidarity, and frequent affirmation of family strengths are emphasized.

In a randomized controlled trial, [8][Level of evidence: I] 183 (71%) of 257 families screened were identified as at risk for poor outcomes; 81 (44%) of these at-risk families participated in the trial. Family functioning was classified into one of five groups:

- Two functional groups:
  - Supportive families.
  - Conflict-resolving families.
- Three potentially dysfunctional groups:
  - Sullen families.
  - Hostile families.
  - Intermediate-functioning families.

Participants classified as hostile (n = 19), sullen (n = 21), or intermediate (n = 41) were randomly assigned to either the treatment group or a no-treatment control group. [8]

Results showed modest reductions in distress at 13 months postdeath for all participants, with more significant reductions in distress and depression in family members who had initially higher baseline scores on the Brief Symptom Inventory and Beck Depression Inventory.[8] Overall, global family functioning did not change, yet participants classified as sullen or intermediate showed more improvement than those classified as hostile. Results recommend caution in dealing with hostile families to avoid increasing conflict in such families.[8]

# **Psychosocial Treatment of Complicated Grief**

With the development of proposed diagnostic criteria for complicated grief (i.e., prolonged grief disorder), targeted interventions have been tested in two randomized controlled trials. Both studies are of interventions for bereaved persons whose loved ones died from mixed (not necessarily cancer-related) causes.

The first study [9][Level of evidence: I] compared complicated grief treatment (CGT) with interpersonal psychotherapy (IPT) in 83 women and 12 men, aged 18 to 85 years prescreened, who met the criteria for complicated grief. Both interventions consisted of 16 weekly sessions spread out over an average of 19 weeks per participant. IPT is a widely researched, empirically supported treatment intervention for depression.

IPT therapists used an intervention delivered as described in a published manual,[10] using an introductory phase, a middle phase, and a termination phase. During the introductory phase, symptoms were identified, and an inventory of interpersonal relationships was completed, with a focus on interpersonal problems. Connections between symptoms, interpersonal problems, and grief were identified and discussed.[9]

During the middle phase, these interpersonal problems and issues of grief were addressed. Patients were encouraged to develop a realistic relationship with the deceased, to recognize both positive and negative aspects of the loss, and to invest in new, positive relationships.[9]

During the termination phase, gains were identified and reviewed, future plans were made and feelings about termination were discussed.[9]

CGT was also delivered according to a manual protocol, also organized into three phases. In the introductory phase, therapists described the distinctions between normal and complicated grief. They also explained the concept of dual processing, or the notion that grief progresses best when attention alternates between (a) a focus on loss and (b) a focus on restoration and future. Thus, the introductory phase included both a discussion of the loss and an identification of future goals and aspirations.

Throughout the middle phase, attention alternated between the themes of loss/grief and future/restoration. A unique characteristic of CGT was the concept of revisiting loss via retelling the story of the death. This concept was particularly important for persons inclined to avoid thinking about the trauma of the loss. Specific procedures that were modeled after the "imaginal exposure" component of interventions for post-traumatic stress disorder were utilized for retelling.[9]

The termination phase for the CGT group was similar to that for the IPT group.[9]

Both treatments showed improvements in symptoms, with the CGT group showing a larger percentage of patients responding (51%) than the IPT group (28%). The CGT group also seemed to respond quicker

than the IPT group. A total of 45% of all study participants were taking antidepressants. No significant differences in outcomes were found for those on antidepressant medications.[9]

The second study of complicated grief [11][Level of evidence: II] compared cognitive-behavioral therapy (CBT), offered in two different sequences, with supportive counseling for 54 bereaved persons, all prescreened and found to be experiencing complicated grief.

With researchers hypothesizing that maladaptive thoughts and behaviors are an important component of complicated grief, the CBT interventions consisted of two components (exposure therapy and cognitive restructuring) designed to directly impact grief-related thoughts and behaviors.[11] Participants were randomly assigned to receive one of three treatments:

- Exposure therapy followed by cognitive restructuring.
- Cognitive restructuring followed by exposure therapy.
- Supportive counseling.

Results showed that both CBT groups experienced more improvement in symptoms of complicated grief and general psychopathology than did the supportive counseling group. In component analyses, the exposure therapy component was more effective than the cognitive restructuring component; the sequence of exposure therapy first, followed by cognitive restructuring, produced the best results.[<u>11</u>]

## Pharmacologic Treatment of Bereavement-related Depression

The clinical decision on whether to provide pharmacologic treatment for depressive symptoms in the context of bereavement is controversial and not very extensively studied. Some health care professionals argue that distinguishing the sadness and distress of normal grief from the sadness and distress of depression is difficult, and pharmacologic treatment of a normal emotional process is not warranted. However, three open-label trials and one randomized controlled trial of treatment of bereavement-related depression with antidepressants have been reported (see <u>Table 1</u>).

The open-label trials evaluated desipramine, [<u>12</u>] nortriptyline, [<u>13</u>] and bupropion sustained release. [<u>14</u>][<u>Level of evidence: II</u>] The studies included patients experiencing depressive symptoms after the deaths of their loved ones. The depressive symptoms were evaluated using the Hamilton Depression Rating Scale (HDRS). All studies evaluated intensity of grief using select grief assessment questionnaires.

Data from these studies suggest that antidepressants are well tolerated and improve symptoms of depression. Data also suggest that the intensity of grief improved but that the improvement was consistently less in comparison with the symptoms of depression. Limitations of these studies include open-label treatment and small sample sizes.

The only randomized controlled study conducted to date [15][Level of evidence: I] compared nortriptyline with placebo for the treatment of bereavement-related major depressive episodes. Nortriptyline was also compared with two other treatments, one combining nortriptyline with IPT and the other combining placebo with IPT. Eighty subjects, aged 50 years or older, were randomly assigned to one of the four treatment groups: nortriptyline (n = 25), placebo (n = 22), nortriptyline plus IPT (n = 16), and placebo plus IPT (n = 17).

The 17-item HDRS was used to assess depressive symptoms. Remission was defined as a score of 7 or lower for 3 consecutive weeks. The remission rates for the four groups were as follows: nortriptyline alone, 56%; placebo alone, 45%; nortriptyline plus IPT, 69%; placebo plus IPT, 29%. Nortriptyline was superior to placebo in achieving remission (P < .03).[15]

The combination of nortriptyline with IPT was associated with the highest remission rate and highest rate of treatment completion. The study did not show a difference between IPT and placebo, possibly owing to specific aspects of the study design, including short duration of IPT (mean no. of days, 49.5) and small sample size.[15] The high remission rate with placebo was another important limitation of the study. Consistent with previous open-label studies and for all four groups, improvement in grief intensity was less than improvement in depressive symptoms.

In summary, all of the antidepressant studies conducted to date suggest that the magnitude of reduction and rate of improvement in grief symptoms are slower than the decrease in magnitude and rate of improvement in depressive symptoms. One group of researchers [15] provides possible explanations for this phenomenon, arguing that depressive symptoms may be more responsive to pharmacological intervention because they are directly related to biological dysregulation and neurochemical changes. The other possibility is that the persistence of grief without depressive symptoms is not pathological—it might be a normal and necessary consequence of the bereavement process.

# Table 1. Pharmacological Intervention Studies of Bereavement-relatedDepression

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Citation	Туре	Subjects	Age (y)	Treatment	Results
[ <u>12</u> ]	Open label	8 women, 2 men	Mean not reported; range, 26–65	Desipramine	7 subjects much improved <sup>a</sup> ; 2 subjects minimally improved; 1 dropout
[ <u>13</u> ]	Open label	8 women, 5 men	Mean, 71.1; range, 61–78	Nortriptyline	Mean HDRS scores decreased 67.9%; no dropouts
[ <u>14</u> ]	Open label	17 women, 5 men	Mean, 63.5; range, 45–83	Bupropion SR	Mean HDRS scores decreased 54%; 8 dropouts
[ <u>15</u> ] <sup>b</sup>	Randomized controlled	58 women, 22 men	Mean range for 4 groups, 63.2– 69.5	Nortriptyline vs. placebo vs. NTP+IPT or PLA+IPT	NTP statistically significant compared to PLA; NTP+IPT group had lowest attrition rate

HDRS = Hamilton Depression Rating Scale; IPT = interpersonal psychotherapy; NTP = nortriptyline; PLA = placebo; SR = sustained release.

<sup>a</sup>Improvement based on the Clinical Global Impression (CGI) rating after review of the decline in HDRS score.

<sup>b</sup>See text for details.

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Back to Top

# **Children and Grief**

At one time, children were considered miniature adults, and their behaviors were expected to be modeled as such.[1] Today there is a greater awareness of developmental differences between childhood and other developmental stages in the human life cycle. Differences between the grieving process for children and the grieving process for adults are recognized. It is now believed that the real issue for grieving children is not whether they grieve, but how they exhibit their grief and mourning.[1]

The primary difference between bereaved adults and bereaved children is that intense emotional and behavioral expressions are not continuous in children. A child's grief may appear more intermittent and briefer than that of an adult, but in fact a child's grief usually lasts longer.[<u>1-3</u>]

The work of mourning in childhood needs to be addressed repeatedly at different developmental and chronological milestones. Because bereavement is a process that continues over time, children will revisit the loss repeatedly, especially during significant life events (e.g., going to camp, graduating from school, marrying, and experiencing the births of their own children). Children must complete the grieving process, eventually achieving resolution of grief.

Although the experience of loss is unique and highly individualized, several factors can influence a child's grief:[2-4]

- Age.
- Personality.
- Stage of development.
- Previous experiences with death.
- Previous relationship with the deceased.
- Environment.
- Cause of death.
- Patterns of interaction and communication within the family.
- Stability of family life after the loss.
- How the child's needs for sustained care are met.
- · Availability of opportunities to share and express feelings and memories.
- · Parental styles of coping with stress.
- Availability of consistent relationships with other adults.

Children do not react to loss in the same ways as adults and may not display their feelings as openly as adults do. In addition to verbal communication, grieving children may employ play, drama, art, school work, and stories. [5] Bereaved children may not withdraw into preoccupation with thoughts of the deceased person; they often immerse themselves in activities (e.g., they may be sad one minute and then playing outside with friends the next). Families often incorrectly interpret this behavior to mean the child does not really understand or has already gotten over the death. Neither assumption may be true; children's minds protect them from thoughts and feelings that are too powerful for them to handle.

Grief reactions are intermittent because children cannot explore all their thoughts and feelings as rationally as adults can. Additionally, children often have difficulty articulating their feelings about grief. A grieving child's behavior may speak louder than any words he or she could speak. Strong feelings of anger and fear of abandonment or death may be evident in the behaviors of grieving children. Children often play death games as a way of working out their feelings and anxieties in a relatively safe setting. These games are familiar to the children and provide safe opportunities to express their feelings.[1,2]

# **Grief and Developmental Stages**

Death and the events surrounding it are understood differently depending on a child's age and developmental stage (see <u>Table 2</u>).

#### Infants

Although infants do not recognize death, feelings of loss and separation are part of a developing death awareness. Children who have been separated from their mothers and deprived of nurturing can exhibit changes such as listlessness, quietness, unresponsiveness to a smile or a coo, physical changes (including weight loss), and a decrease in activity and lack of sleep.[6]

#### Ages 2 to 3 years

In this age range, children often confuse death with sleep and can experience anxiety. In the early phases

of grief, bereaved children can exhibit loss of speech and generalized distress.[3,6]

#### Ages 3 to 6 years

In this age range, children view death as a kind of sleep: the person is alive, but in some limited way. They do not fully separate death from life and may believe that the deceased continues to live (for instance, in the ground where he or she was buried) and often ask questions about the activities of the deceased person (e.g., how is the deceased eating, going to the toilet, breathing, or playing?). Young children can acknowledge physical death but consider it a temporary or gradual event, reversible and not final (like leaving and returning, or a game of peek-a-boo). A child's concept of death may involve magical thinking, i.e., the idea that his or her thoughts can cause actions. Children may feel that they must have done or thought something bad to become ill or that a loved one's death occurred because of some personal thought or wish. In response to death, children younger than 5 years will often exhibit disturbances in eating, sleeping, and bladder or bowel control.[3,6]

#### Ages 6 to 9 years

It is not unusual for children in this age range to become very curious about death, asking very concrete questions about what happens to one's body when it stops working. Death is personified as a separate person or spirit: a skeleton, ghost, angel of death, or bogeyman. Although death is perceived as final and frightening, it is not universal. Children in this age range begin to compromise, recognizing that death is final and real but mostly happens to older people (not to themselves). Grieving children can develop school phobias, learning problems, and antisocial or aggressive behaviors; can exhibit hypochondriacal concerns; or can withdraw from others. Conversely, children in this age range can become overly attentive and clinging. Boys may show an increase in aggressive and destructive behavior (e.g., acting out in school), expressing their feelings in this way rather than by openly displaying sadness. When a parent dies, children may feel abandoned by both their deceased parent and their surviving parent, since the surviving parent is frequently preoccupied with his or her own grief and is less able to emotionally support the child.[<u>3,6</u>]

#### Ages 9 years and older

By the time a child is 9 years old, death is understood as inevitable and is no longer viewed as a punishment. By the time the child is 12 years old, death is viewed as final and universal.[3,6]

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Age	Understanding of Death	Expressions of Grief
Infancy to 2	Is not yet able to understand death.	Quietness, crankiness, decreased activity, poor sleep, and weight loss.
years	Separation from mother causes changes.	
2–6 years	Death is like sleeping.	Asks many questions (How does she go to the bathroom? How does she eat?).
		Problems in eating, sleeping, and bladder and bowel control.
		Fear of abandonment.
		Tantrums.
	Dead person continues to live and function in some ways.	Magical thinking (Did I think something or do something that caused the death? Like when I said I hate you and I wish you would die?).
	Death is temporary, not final.	
	Dead person can come back to life.	
6–9 years	Death is thought of as a person or spirit (skeleton, ghost, bogeyman).	Curious about death.
	spint (skeleton, ghost, bogeyman).	Asks specific questions.
		May have exaggerated fears about school.
	Death is final and frightening.	May have aggressive behaviors (especially boys).
		Some concerns about imaginary illnesses.
	Death happens to others; it will not happen to ME.	May feel abandoned.
9 and older	Everyone will die.	Heightened emotions, guilt, anger, shame.
		Increased anxiety over own death.
		Mood swings.
	Death is final and cannot be changed.	Fear of rejection; not wanting to be different from peers.

Even I will die.	Even I will die.	Changes in eating habits.
		Sleeping problems.
		Regressive behaviors (loss of interest in outside activities).
		Impulsive behaviors.
		Feels guilty about being alive (especially related to death of a brother, sister, or peer).

In American society, many grieving adults withdraw into themselves and limit communication. In contrast, children often talk to those around them (even strangers) as a way of watching for reactions and seeking clues to help guide their own responses. It is not uncommon for children to repeatedly ask baffling questions. For example, a child may ask, "I know Grandpa died, but when will he come home?" This is thought to be a way of testing reality for the child and confirming the story of the death.

#### Issues for grieving children

There are three prominent themes in the grief expressions of bereaved children:

- 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?[2,7]

#### Did I cause the death to happen?

Children often engage in magical thinking, believing they have magical powers. If a mother says in exasperation, "You'll be the death of me," and later dies, her child may wonder whether he or she actually caused the death. Likewise, when two siblings argue, it is not unusual for one to say (or think), "I wish you were dead." If that sibling were to die, the surviving sibling might think that his or her thoughts or statements actually caused the death.

#### Is it going to happen to me?

The death of a sibling or other child may be especially difficult because it strikes so close to the child's own peer group. If the child also perceives that the death could have been prevented (by either a parent or doctor), the child may think that he or she could also die.

## Who is going to take care of me?

Because children depend on parents and other adults for their safety and welfare, a child who is grieving the death of an important person in his or her life might begin to wonder who will provide the care that he or she needs now that the person is gone.

# Interventions for Grieving Children

There are interventions that may help to facilitate and support the grieving process in children.

## Explanation of death

Silence about death (which indicates that the subject is taboo) does not help children deal with loss. When death is discussed with a child, explanations should be kept as simple and direct as possible. Each child needs to be told the truth with as much detail as can be comprehended at his or her age and stage of development. Questions should be addressed honestly and directly. Children need to be reassured about their own security (they frequently worry that they will also die or that their surviving parent will go away). A child's questions should be answered, and the child's processing of the information should be confirmed.

## **Correct language**

Although it is a difficult conversation to initiate with children, any discussion about death must include proper words (e.g., *cancer*, *died*, or *death*). Euphemisms (e.g., "he passed away," "he is sleeping," or "we lost him") should never be used because they can confuse children and lead to misinterpretations.[<u>3,8</u>]

#### **Planning rituals**

After a death occurs, children can and should be included in the planning of and participation in mourning rituals. As with bereaved adults, these rituals help children memorialize loved ones. Although children should never be forced to attend or participate in mourning rituals, their participation should be encouraged. Children can be encouraged to participate in the aspects of funeral or memorial services with which they feel comfortable. If the child wants to attend the funeral (or wake or memorial service), it is important that a full explanation of what to expect is given in advance. This preparation should include the

layout of the room, who might be present (e.g., friends and family members), what the child will see (e.g., a casket and people crying), and what will happen. Surviving parents may be too involved in their own grief to give their children the attention they need. Therefore, it is often helpful to identify a familiar adult friend or family member who will be assigned to care for a grieving child during a funeral.[8]

#### References and resources for grieving children

There is a wealth and variety of helpful resources (books and videos) that can be shared with grieving children.

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# **Cross-cultural Responses to Grief and Mourning**

Grief, whether in response to the death of a loved one, to the loss of a treasured possession, or to a significant life change, is a universal occurrence that crosses all ages and cultures. However, there are many aspects of grief about which little is known, including the role that cultural heritage plays in an individual's experience of grief and mourning.[1,2] Attitudes, beliefs, and practices regarding death and grief are characterized and described according to multicultural context, myth, mysteries, and mores that describe cross-cultural relationships.[2]

The potential for contradiction between an individual's intrapersonal experience of grief and his or her cultural expression of grief can be explained by the prevalent (though incorrect) synonymous use of the terms *grief* (the highly personalized process of experiencing reactions to perceived loss) and *mourning* (the socially or culturally defined behavioral displays of grief).[3,4]

An analysis of the results of several focus groups, each consisting of individuals from a specific culture, reveals that individual, intrapersonal experiences of grief are similar across cultural boundaries. This is true even considering the culturally distinct mourning rituals, traditions, and behavioral expressions of grief experienced by the participants. Health care professionals need to understand the part that may be played by cultural mourning practices in an individual's overall grief experience if they are to provide culturally sensitive care to their patients.[1]

In spite of legislation, health regulations, customs, and work rules that have greatly influenced how death is managed in the United States, bereavement practices vary in profound ways depending on one's cultural background. When assessing an individual's response to the death of a loved one, clinicians should identify and appreciate what is expected or required by the person's culture. Failing to carry out expected rituals can lead to an experience of unresolved loss for family members.[5] This is often a daunting task when health care professionals serve patients of many ethnicities.[2]

Helping family members cope with the death of a loved one includes showing respect for the family's cultural heritage and encouraging them to decide how to commemorate the death. Clinicians consider the following five questions particularly important to ask those who are coping with the emotional aftermath of the death of a loved one:

- 1. What are the culturally prescribed rituals for managing the dying process, the body of the deceased, the disposal of the body, and commemoration of the death?
- 2. What are the family's beliefs about what happens after death?
- 3. What does the family consider an appropriate emotional expression and integration of the loss?
- 4. What does the family consider to be the gender rules for handling the death?
- 5. Do certain types of death carry a stigma (e.g., suicide), or are certain types of death especially traumatic for that cultural group (e.g., death of a child)?[6]

Death, grief, and mourning are universal and natural aspects of the life process. All cultures have evolved practices that best meet their needs for dealing with death. Hindering these practices can disrupt the necessary grieving process. Understanding these practices can help clinicians to identify and develop ways to treat patients of other cultures who are demonstrating atypical grief.[7] Given current ethnodemographic trends, health care professionals need to address these cultural differences in order to best serve these populations.[2]

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# **Current Clinical Trials**

Check NCI's PDQ Cancer Clinical Trials Registry for U.S. supportive and palliative care trials about <u>loss</u>, <u>grief</u>, <u>and bereavement</u> that are now accepting participants. The list of trials can be further narrowed by location, drug, intervention, and other criteria.

General information about clinical trials is also available from the <u>NCI Web site</u>.

Back to Top

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# Call 1-800-4-CANCER

For more information, U.S. residents may call the National Cancer Institute's (NCI's) Cancer Information Service toll-free at 1-800-4-CANCER (1-800-422-6237) Monday through Friday from 8:00 a.m. to 8:00 p.m., Eastern Time. A trained Cancer Information Specialist is available to answer your questions.

### Chat online

The <u>NCI's LiveHelp®</u> online chat service provides Internet users with the ability to chat online with an Information Specialist. The service is available from 8:00 a.m. to 11:00 p.m. Eastern time, Monday through Friday. Information Specialists can help Internet users find information on NCI Web sites and answer questions about cancer.

#### Write to us

For more information from the NCI, please write to this address:

NCI Public Inquiries Office Suite 3036A 6116 Executive Boulevard, MSC8322 Bethesda, MD 20892-8322

#### Search the NCI Web site

The <u>NCI Web site</u> provides online access to information on cancer, clinical trials, and other Web sites and organizations that offer support and resources for cancer patients and their families. For a quick search, use the search box in the upper right corner of each Web page. The results for a wide range of search terms will include a list of "Best Bets," editorially chosen Web pages that are most closely related to the search term entered.

There are also many other places to get materials and information about cancer treatment and services. Hospitals in your area may have information about local and regional agencies that have information on finances, getting to and from treatment, receiving care at home, and dealing with problems related to cancer treatment.

#### **Find Publications**

The NCI has booklets and other materials for patients, health professionals, and the public. These publications discuss types of cancer, methods of cancer treatment, coping with cancer, and clinical trials. Some publications provide information on tests for cancer, cancer causes and prevention, cancer statistics, and NCI research activities. NCI materials on these and other topics may be ordered online or printed directly from the <u>NCI Publications Locator</u>. These materials can also be ordered by telephone from the Cancer Information Service toll-free at 1-800-4-CANCER (1-800-422-6237).

# Back to Top

# Changes to This Summary (08/31/2010)

The PDQ cancer information summaries are reviewed regularly and updated as new information becomes available. This section describes the latest changes made to this summary as of the date above.

This summary was renamed from Bereavement, Mourning, and Grief.

Editorial changes were made to this summary.

Back to Top

# **Questions or Comments About This Summary**

If you have questions or comments about this summary, please send them to Cancer.gov through the Web site's <u>Contact Form</u>. We can respond only to email messages written in English.

Back to Top

# **More Information**

### About PDQ

• PDQ® - NCI's Comprehensive Cancer Database.

Full description of the NCI PDQ database.

### Additional PDQ Summaries

PDQ® Cancer Information Summaries: Adult Treatment

Treatment options for adult cancers.

PDQ® Cancer Information Summaries: Pediatric Treatment

Treatment options for childhood cancers.

• PDQ® Cancer Information Summaries: Supportive and Palliative Care

Side effects of cancer treatment, management of cancer-related complications and pain, and psychosocial concerns.

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Tests or procedures that detect specific types of cancer.

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Risk factors and methods to increase chances of preventing specific types of cancer.

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Genetics of specific cancers and inherited cancer syndromes, and ethical, legal, and social concerns.

PDQ® Cancer Information Summaries: Complementary and Alternative Medicine

Information about complementary and alternative forms of treatment for patients with cancer.

# Important:

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Back to Top

# About This PDQ Summary

# **Purpose of This Summary**

This PDQ cancer information summary for health professionals provides comprehensive, peer-reviewed, evidence-based information about how individuals cope with grief, bereavement, and mourning. It is intended as a resource to inform and assist clinicians who care for cancer patients. It does not provide formal guidelines or recommendations for making health care decisions.

# **Reviewers and Updates**

This summary is reviewed regularly and updated as necessary by the <u>PDQ Supportive and Palliative Care</u> <u>Editorial Board</u>. Board members review recently published articles each month to determine whether an article should:

- be discussed at a meeting,
- be cited with text, or
- replace or update an existing article that is already cited.

Changes to the summaries are made through a consensus process in which Board members evaluate the strength of the evidence in the published articles and determine how the article should be included in the summary.

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# Levels of Evidence

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Back to Top

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