



# Brain Tumour Australia Information

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### Help, Care & Support cont.

#### 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 behaviours 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 honour the death.

Important questions that should be asked of people who are dealing with the loss of a loved one include:

- What are the cultural rituals for coping with dying, the deceased person's body, the final arrangements for the body, and honouring the death?
- What are the family's beliefs about what happens after death?
- What does the family feel is a normal expression of grief and the acceptance of the loss?
- What does the family consider to be the roles of each family member in handling the death?
- 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 health professionals recognize the grieving process in patients of other cultures.

#### Grief & Loss

*The following overview is presented from information provided by the National Cancer Institute [NCI] Bethesda, USA*

##### 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 their experience with a brain tumour, the way the illness progressed, the person's cultural and religious background, coping skills, mental history, support systems, and the person's social and financial status.

The terms grief, bereavement, and mourning are often used in place of each other, but they have different meanings.

**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.



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#### Care & Support—Grief & Loss cont.

**Bereavement** is the period after a loss during which grief is experienced and mourning occurs. 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.

**Mourning** is the process by which people adapt to a loss. 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 the following 3 phases

- The urge to bring back the person who died.
- Disorganization and sadness.
- 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 the following 4 phases:

- Phase before the diagnosis.
- The acute phase.

- The chronic phase.
- 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 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 brain tumour 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 some brain tumours

In the **recovery phase**, people cope with the mental, social, physical, religious, and financial effects of a brain tumour. The final (terminal) phase of a life-threatening illness occurs when death is likely. The focus changes from curing the illness or prolonging life, to providing comfort and relief from pain. Religious concerns are often the focus during this 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. It includes all of the thinking, feeling, cultural, and social reactions to an expected death that are felt by the patient and family.

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.



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#### Anticipatory Grief cont.

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.

#### Phases of Grief

The process of bereavement may be described as having 4 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.** to become withdrawn

#### Complicated Grief

Complicated grief reactions require more complex therapies than uncomplicated grief reactions. Adjustment disorders (especially depressed and anxious mood or disturbed

emotions and behaviour), 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.



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#### Treatment of Grief

Most of the support that people receive after a loss comes from friends and family. Doctors and nurses may also be a source of support. For people who experience difficulty in coping with their loss, grief counselling or grief therapy may be necessary.

Grief counselling helps mourners with normal grief reactions work through the tasks of grieving. Grief counselling 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 counselling 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 more serious 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 behaviour 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, 6 tasks may be used to help a mourner work through grief:

1. Develop the ability to experience, express, and add just 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. Re-establish relationships and understand that others may have difficulty empathizing with the grief they experience.
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.