

## Mourning a Loved One: A Guide to Grieving

*What the heart has once owned and had, it shall never lose.*

Henry Ward Beecher

The death of loved ones to pulmonary hypertension is all too real. And with it comes the long and hard work of grieving. You remain an important part of our community, and PHA would like to support you for as long as you need. As a starting point, we have developed this resource to help anyone who is grieving a loved one's death better understand the grieving process.

Grieving is a normal and necessary experience. It's also a uniquely individual experience — how you mourn will differ from how others do. There is no right or wrong way, but there are certain things about the grieving process that may be helpful for you to know.

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*Death ends a life, not a relationship.*

Robert Benchley

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Grieving is NOT about "leaving behind" your loved one. It is about incorporating the loss into your life and maintaining a bond with the deceased while moving forward. Grief can be confusing: you may simultaneously experience terrible pain and great relief. You may feel like you're going crazy. You may feel fury and joy, longing, loneliness, anger, guilt, anguish, frustration and impotence. Everything you feel is normal.

It's also important to keep in mind that the intensity doesn't last forever. Pamela Brown, who lost her 22-year-old daughter Marchelle to PH, told us the following about her conversation with a dad who had lost a child twenty years earlier:

*He said 'you know what, it will probably take you about six months before it won't hurt as bad. You will always have the pain, but you learn to manage it and live with it.' That was the most helpful advice anyone has given me; it gave me hope to know there would be a light at the end of the tunnel.*

The following reflects the insights from some of those who are considered "experts" in the field of bereavement as well as the wisdom gained by members of our own community who have experienced the death of a loved one from pulmonary hypertension.

### Models of Grief

Some people who are mourning the death of a loved one find "models of grief" helpful as a way to understand the complicated emotions they are experiencing. But it is also important to remember that the actual experience of grief tends to be less clear-cut. In the words of Sandra Bertman of the National Center for Death Education, "the phases of grief may overlap, may be of varying and unpredictable duration, occur in any order, may be present simultaneously, and may disappear or reappear at random."

William Worden suggests that the following “Tasks of Mourning” are the necessary stages each person needs to go through:

- Accepting the reality of the loss
- Experiencing the feelings of grief
- Adjusting to an environment in which the deceased is missing
- Investing emotional energy in other relationships (*not to “let go” of the deceased, but to pursue and enjoy relationships with others in one’s life*).

Elizabeth Kubler-Ross’ “Stages of Loss” describe the steps many people experience through the bereavement process:

- Shock and denial: *“This can’t be real.”*
- Anger: *“How could this happen to me?”*
- Bargaining: *“If he/she isn’t really dead, I will \_\_\_\_.”*
- Depression
- Acceptance

Both Pam Brown and Rev. Steve White, who lost his 22-year-old-daughter Christen to PH, talk about grief using the image of “waves.” Here’s how Steve described it:

*Grief is like a wave because it comes in cycles. There are big waves and small ones that come at different times with different emotions. The only difference between grief and a wave is that in grief you can’t see the big waves that are coming. You begin to think that the worst is over and then all of a sudden you start sobbing, and falling apart.*

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*I would say no, I just need to cry for a few minutes. Waves of emotions that continue and will continue. I can’t imagine trying to hold it in.*

Pam Brown

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## Experiencing Grief

Grief involves every part of ourselves: mental, emotional, physical and behavioral. While no two survivors will have the same experience, it may be helpful to know that all of the following reactions are considered “normal” as a person grieves.

### *Mental*

You may feel disoriented, confused, anxious, in pain, and disorganized. You might go through periods of euphoria or depression. Many survivors “sense” the deceased through scent or sight, whether in dreams or while awake.

### *Emotional*

You may feel a range of emotions, often contradictory. These include longing, loneliness, anger, guilt, anguish, frustration and impotence.

### *Physical*

Physical symptoms may include sleep disorders, shortness of breath, an empty feeling in the stomach, tightness in the throat, muscle weakness and tremors. Such symptoms may appear similar to an anxiety disorder.

### *Behavioral*

Grieving may be accompanied by restlessness and hyperactivity. You may have more volatile reactions and become easily irritated.

## How Long Does Grief Last?

There is no definite timeline for grieving. If you are concerned that your grief may be continuing too long or is otherwise beyond “normal,” you may want to consult a mental health professional. Your insurance may cover counseling, or a local support group or hospice center may be able to connect you with a therapist.

Holidays, big life changes, or other events that may remind you of your loved one can bring back the feelings of grief. These reoccurrences are typically less intense than the initial bereavement period. Planning for these events by asking for additional support in advance, creating new rituals or just planning to keep busy may help you through these times of year.

## Coping Mechanisms

- **Find support.** Whether it’s someone to listen or someone to help run errands, social support will help you through this painful time. Family can be an important source of support; you may also want to find a bereavement group to connect with others who know what you’re experiencing. A counselor or therapist can also be beneficial.

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**Resource to Check Out: Tear Soup**  
by Pat Schweibert, Chuck DeKlyen  
and Taylor Bills.

*Tear Soup* tells the story of Grandy, who recently lost “someone close.” Grandy shares her recipe for “tear soup” to help others who are grieving. *Tear Soup* is appropriate for all ages.

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- **Communicate your needs.** Your friends might feel uncertain about whether to bring up your loved one’s death. They may also offer less support as time passes. Tell them whether you want to talk about your loved one or not at that moment; don’t hesitate to reach out to them when you need additional support. Understand that they may not always be able to offer you the support you need, but it is always okay to ask.

Pulmonary hypertension is familial on Betty Lou Wojciechowski’s husband’s side of the family. Before her husband Jerry died of PH, Betty Lou and Jerry lost two sons, Matthew at four years and Michael in his early 20s. According to Betty Lou, being able to talk about those who have died is critically important to the healing process:

*Through my losses, what I know is, ‘I want to talk about the person who died.’ The only connection I have to him is his memories. People avoid talking to mourning family members because they don’t want to cause distress, but healing can occur when you talk about it.*

- **Take care of your physical health.** As a caregiver you have already invested significant amounts of your energy and focus, and you may be near burnout. While nothing can take away the pain of grieving, taking care of your physical health can contribute to your ability to cope with stress.
- **Don’t judge your grief.** There is no right or wrong way to grieve. A sense that “grief should be —” can impede a healthy grieving process.

As Steve White says, “There are different ways of dealing with grief ...

*Some people after experiencing a loss fill their schedule completely with lunches, going, out, meetings, trips and everything else and that is what makes them feel better. That’s not me. I feel best when I’m relaxing instead of filling my time up with other things.*

- **Face your grief.** There will be days when you simply can’t, and that is normal. But over time it’s imperative to face your grief and allow yourself to feel.

- **Express your grief.** It is important to express grief, anger and your other emotions. Some survivors find it useful to explore new modes of expression such as art.
- **Grow.** Many people use grief as an opportunity to find a purpose or mission, or explore new outlets.
- **Utilize rituals.** Rituals such as funerals help survivors symbolically accept the reality of their loved one's death. Some survivors choose to create their own ritual events.

### Going On ...

Words of wisdom from Betty Lou Wojciechowski:

*People ask me this every day, 'how do you deal with this?' I feel like the sun comes up every day and you have a choice: you can either curl up in a ball or live your life. If you wake up alive then you know that God has given you the choice to live abundantly.*

### Resources

The following is a partial list of resources that may help you.

*General:*

**The Hospice Foundation of America** offers short articles on grieving and a bereavement newsletter.

<http://www.hospicefoundation.org/>

**GriefNet** offers more than 50 email groups and other online resources for people coping with grief and loss.

<http://griefnet.org/>

**Open to Hope** provides information and resources for people who have experienced loss and a forum where people who have experienced loss can learn from and help each other. <http://www.opentohope.com/>

**The Association for Death Education and Counseling** offers an online database of professionals with specialized education and/or certification in dying, death and bereavement.

[http://www.adec.org/source/FindAThanatologist/index.cfm?Section=Find\\_A\\_Thanatologist](http://www.adec.org/source/FindAThanatologist/index.cfm?Section=Find_A_Thanatologist)

*For Bereaved Parents and Grandparents:*

**The Compassionate Friends** self-help bereavement organization offers friendship, understanding, and hope to families following the death of a child of any age from any cause. There are over 600 chapters in all 50 states.

<http://www.compassionatefriends.org/>

**Bereaved Parents of the USA** (BP/USA) is a national non-profit self-help group that offers support, understanding, compassion and hope especially to those struggling to rebuild their lives after the death of their children, grandchildren or siblings. <http://www.bereavedparentsusa.org/>

*For Bereaved Children:*

**Comfort Zone Camp** is a nonprofit bereavement camp for children who have experienced the death of a parent, sibling, or primary caregiver. The free camps include confidence-building programs and age-based support groups that break the emotional isolation grief often brings. Comfort Zone Camps are offered to children 7-17, and are held year-round in California, Massachusetts, New Jersey, Virginia and Texas. <http://www.comfortzonecamp.org/>

**The National Alliance for Grieving Children** promotes awareness of the needs of children and teens grieving a death and provides education and resources for anyone who wants to support them. <http://www.nationalallianceforgrievingchildren.org/about-us>

**KidsAid.com** is an email support group for kids who are grieving. KidsAid is an offshoot of GriefNet.org. <http://www.kidsaid.com/>

## Sources

PHA drew from the following sources in developing this guide to grieving:

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\* HelpGuide.Org (2010, November). *Coping with Grief and Loss: Support for Grieving and Bereavement*. Retrieved December 13, 2010, from [http://helpguide.org/mental/grief\\_loss.htm](http://helpguide.org/mental/grief_loss.htm)

\* Worden, J.W., (1982). *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner*. New York: Springer.

\* Bertman, Sumpter and Green, "Bereavement and Grief," in *Introduction to Clinical Medicine*, ed. Harry L. Green (Philadelphia: B. C. Decker, 1991) p. 682.

\* Kubler-Ross, Elisabeth. (1969). *On Death and Dying*. New York: Macmillan.