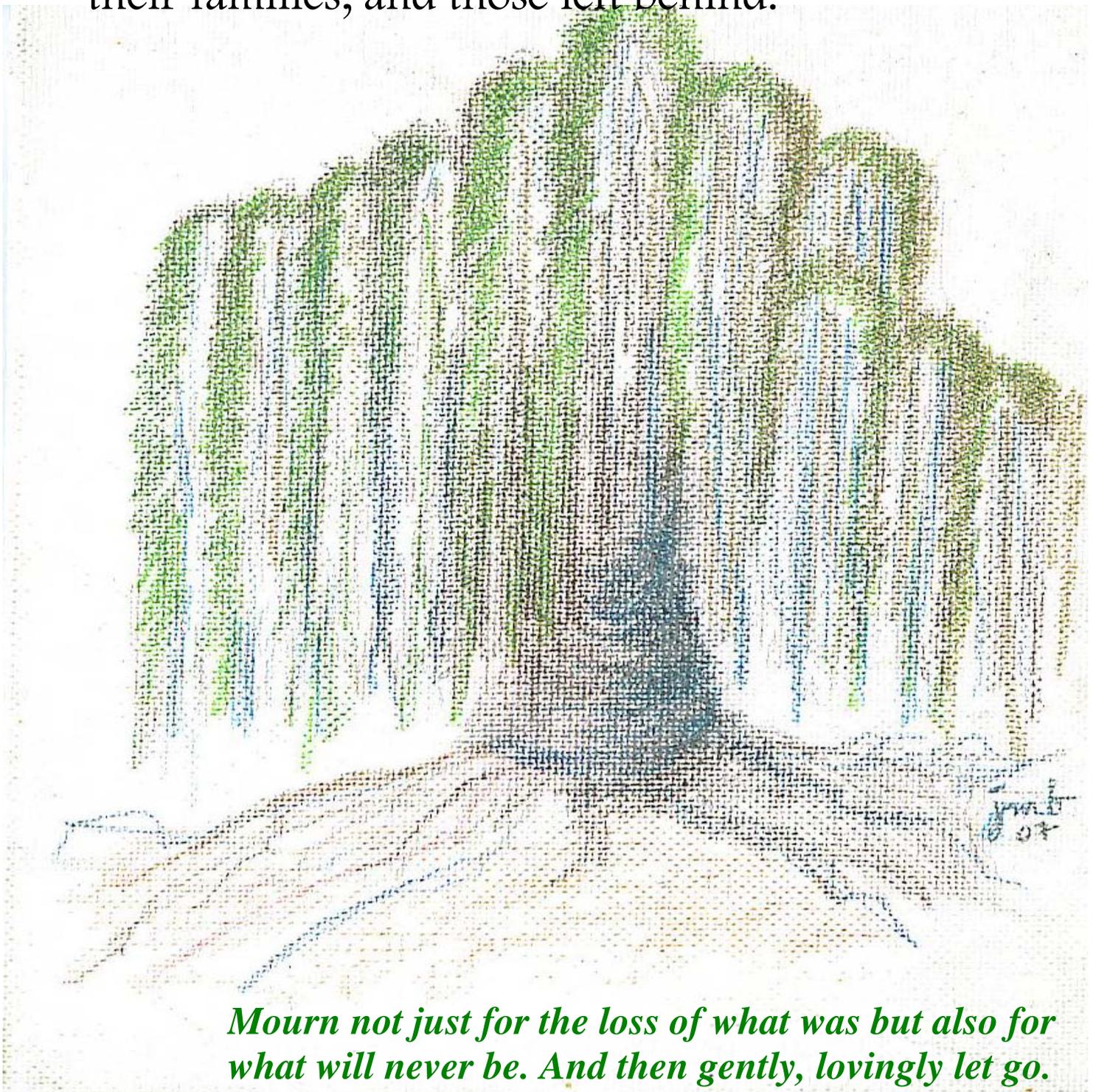


# LOSS & GRIEF:

A manual to help those living with ALS,  
their families, and those left behind.



*Mourn not just for the loss of what was but also for  
what will never be. And then gently, lovingly let go.*

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The ALS Association, St. Louis Regional Chapter is dedicated to improving the quality of life for those affected by Amyotrophic Lateral Sclerosis, educating the community, and supporting research.

To learn more about the services provided through The ALS Association, St. Louis Regional Chapter in Eastern Missouri as well as Central and Southern Illinois: visit our website at [www.alsa-stl.org](http://www.alsa-stl.org)

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# LOSS AND GRIEF

As you deal with your diagnosis of ALS and its effects on your life, you and your family will be confronted with numerous changes and losses. You will face the loss of physical abilities coupled with changes in your role and responsibilities within your family and your community. In addition, you will be facing the inevitable loss of life, while trying to understand and reconcile the experience of having ALS. The degree of loss you experience with each change will be determined by the importance you and your family place on that item or ability lost. You should know, however, that each loss you face, whether you deem it “big” or “small,” will result in some level of grief for both you and your family members.

Grief is an automatic process that is experienced by everyone who faces loss. Often, grief is identified solely with mourning and death. However, it occurs with every loss in your life, such as moving, losing your job, divorce, the death of a pet, ending a relationship, or being diagnosed with a serious illness. You should be aware of this occurrence and understand its impact. Not only may you feel a variety of emotions due to grief, but it may affect you physically, mentally, or spiritually. As you identify losses, it is important that you recognize your reactions to them and allow yourself time to process, adjust, and grieve. You may want to consider expressing your feelings and experiences with someone you trust, such as a friend, family member, clergy, or professional counselor or social worker.

Once a PALS's journey has ended with ALS, family members will begin a bereavement process through which they will mourn and face a future without their loved one. The grief process may be very different for each family member, depending

on their relationship to the PALS, their chronological age, or their developmental stage. Their closeness to the deceased and their anticipation or preparation for the death will also affect their bereavement process. Grief is as different for each family member as ALS is for each PALS. However, through understanding grief, allowing family members their own time and space, and utilizing tools and resources, each family member can move through their grief in a healthy and productive manner.

This manual is designed to provide you and each of your family members with tools, resources, and information about grief to assist you during this difficult, emotional, and often frightening journey. Remember, confronting grief and working through it can result in higher quality of life during your end stage ALS, both for you and for those you leave behind. But YOU must work through your grief; it is an individual and personal process that entails active participation. To help each of you in this process, this manual is divided by individual and/or age as follows:

- One section is specifically for the PALS, as you adjust to the on-going changes and losses in your life and prepare yourself and your family for the future.
- One section is provided for caregivers and spouses to help educate about grief, offer tips and resources for support, and provide hope for the future you face without your loved one.
- A section for parents and caregivers of children in the family offers information on how children understand and process grief at different ages. It also offers age-appropriate grief resources specifically for children, such as books, websites, and local support groups and camps.

- A pull-out section provides a list of books and websites that are appropriate for children (ages 12 and under), as well as simple educational information about the grief experience.
- A packet of educational materials, helpful tips, and other resources for grief support are compiled for teenagers (ages 13-18).
- An additional packet for young adults (ages 18-25) addresses the special bereavement needs of those individuals who may be living out of the home or away at college, but probably have do not have the social network or emotional experience for dealing with death and grief.

This entire book is intended as a tool for addressing end of life issues, facilitating discussion between family members, and helping educate and prepare the family for an uncertain future. Please note, however, that several other resources are available to patients with ALS and their families. To help PALS and family members address and reconcile spiritual matters, The ALS Association, St. Louis Regional Chapter, has pastoral care support available. Additionally, as ALS progresses, many PALS qualify for hospice services. Hospice provides an encompassing package of care to both the patient and the family. In addition to pain management and end of life care, the hospice team includes a chaplain and social worker who can provide emotional and spiritual support to both the PALS and the family members. Many hospice teams also include a bereavement specialist who can work with children on anticipatory grief issues.

The Chapter also has an anticipatory bereavement program for children. ALSA's bereavement coordinator can utilize interactive art activities, play therapies, and age-appropriate books to help children recognize the variety of feelings they may be experiencing while dealing with a loved one's ALS. By acknowledging and normalizing

these emotions, children can process their reactions to the day-to-day realities of living with a loved one with ALS as well as prepare for the eventual death of this person.

To better serve families who do not have access to bereavement services, the Chapter also offers multi-tiered bereavement services for the grieving family. This 13-month bereavement follow-up program includes educational mailings; periodic phone calls; the opportunity for home visits to help with the grief process; this “Loss & Grief” book of educational materials and resource lists; and an annual Memorial Luncheon and Candlelighting Ceremony. Please contact your family’s Patient Services Coordinator or the Chapter bereavement program coordinator for additional support and resources.

# PALS

## LOSS & GRIEF:

Information to help you  
understand and cope with  
your diagnosis of ALS and  
end of life issues

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*“Grieve and mourn for yourself, not once or twice, but again  
and again. Grieving is a great catharsis and comfort  
and a way of keeping yourself composed.”*

*~Morrie Schwartz*

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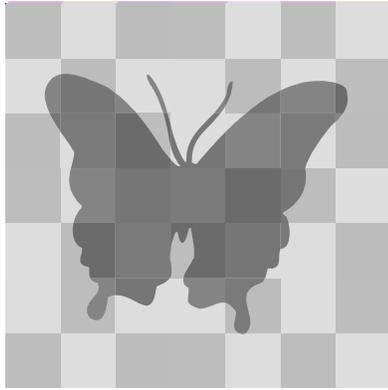
## Where There's Loss, There's Grief

Turning the Losses of neuromuscular disease into growth

by Carol Savell

Neuromuscular disease by its very nature means loss.

As muscle tissue degenerates, whether quickly or over decades, people undergo a series of physical losses. These may include strength and balance, the ability to walk, manual ability, breathing without mechanical help and more.



You may also have lifestyle losses: reduced work hours, an inability to live alone, a need for more help with daily care. Disability can bring interpersonal losses as relationships end or caregiving parents' age and die. For each individual, the losses caused by a progressive neuromuscular disease can be very specific: from the move out of a beloved home to having to stop driving, give up golf or lay down your guitar.

We grieve after any significant loss: divorce, loss of a job, death of a pet, absence of friends, loss of ability and independence. Even positive changes, such as retirement or marriage, involve some loss. You may not identify your feelings about the losses associated with progressive disease as grief. You may have anticipated changes ahead of time and adjusted your life accordingly, with a minimum of obvious emotion. But, even when changes seem to go smoothly, every major loss has an impact. A loss caused by neuromuscular disease can be like losing a part of yourself or your identity. You may feel you no longer know who you are; to survive, you'll need to redefine yourself.

That redefinition is accomplished by grieving - acknowledging and experiencing whatever emotions arise. Completing the grief process allows you to shift priorities and focus on different aspects of yourself. And with that shift,

loss can bring gain - a new way to see yourself and your place in the world.

### Grieving: Why And How

Why do mental health experts believe it's necessary to grieve each significant loss in life?

Libby Coker, a senior social worker at Methodist Hospital in Houston who works with

the MDA clinic there, says the first reason is "to acknowledge what that loss meant to you or what that functional level meant to you, what that job meant to you, what your health meant to you."

*In Letting Go*, the late Morrie Schwartz writes, "I see mourning as a way of paying respect to life."

Second, when people resist grief by trying to squelch their feelings, it may come out in other ways, such as physical illness - ulcers, depression or an overtaxed immune system, Coker says.

Third, grieving helps you to learn better coping skills, appreciate life and achieve growth. Or, as Schwartz, who had ALS, writes, "Having paid my respects through grieving, I can stop brooding over the things I've been deprived of and feel grateful for what I have - people who help me and family and friends whose love I cherish."

The fourth reason Coker cites for healthy grieving: "A person who works through it effectively can also be a major resource to other people who in the future will go through this."

How do you come to terms with your losses in such a way that you could actually help others through their grief?

There's no formula that works for everyone. Many people make healthy adjustments without realizing there's grief

involved. For others, the emotions are powerful and sometimes surprising.

If you feel you may be "stuck" or burdened with an unproductive degree of unacknowledged grief, or emotions that won't let you go, some of the following suggestions may help.

### 1 Admit That You Are Experiencing Loss

In neuromuscular diseases, people know they'll lose some abilities. But knowing ahead of time doesn't protect you from feelings of grief when the loss occurs.

Rather than anticipate their loss, some people indulge in denial - believing that their case will be different, that it won't progress as rapidly as with others, ignoring signs that their abilities are changing.

Coker says, "Once you break through that denial and the shock and you start accepting it, it doesn't mean it's not difficult when those milestones start happening. But maybe you're a little bit more prepared for them and maybe, by that time, you're connected with some people who are like you." If you feel little or nothing when loss occurs, be sure you're not fooling yourself. Watch for physical illnesses, a short temper, a sense of resignation or lingering lethargy - all signs that you're fighting the grief.

The idea of letting strong emotions "out" is frightening to some people. But those who grieve openly find the intensity is only temporary and the emotion is soon spent. Then they can move on, free of the feelings that others are holding in.

### 2 Recognize Emotions That Indicate Grief

Many people think grief means sadness, but other emotions, such as anger, may also be triggered by loss. It may help to examine your past and try to identify the emotion that dominates when you face loss.

In the early 1980s, Wayne Marlatt's limb-girdle muscular dystrophy (LGMD) was causing some problems at work. His employer - before the Americans with Disabilities Act - insisted he leave the job and go on disability. With a wife and two children to support, Marlatt, of Dearborn, Mich., faced this loss with fear.

"If I forced them to take me back and they gave me a job that I couldn't do, then I would get fired and have nothing. This way I had the disability and I had health care coverage," he says.

Marlatt decided not to fight the company. But, faced with the possibility of never working again, he worried: "How are we going to raise our kids? Are the kids going to be able to get to college? All those earthshaking things came."

Over more than 40 years of living with LGMD, Betty Jane Lindsey of Annapolis, Md., found that she experienced depression as a signal that a loss was occurring.

"I noticed I would start having feelings of depression. Then I would think about it and it was usually an unconscious reaction to an added limitation," she says. "In other words, I wasn't consciously aware that I had lost some ground. But I would become aware of the depression, and I'd realize it was telling me something."

### **3 Let Yourself Feel Your Emotions, Whatever They Are**

Whatever emotional form your grief takes, it's probably best to give into it for a while, in a safe and healthy way. Your sorrow, rage, wish to withdraw from life or other feeling can serve a purpose, then make way for new feelings that will help you cope.

After his Charcot-Marie-Tooth disease (CMT) progressed to making walking difficult, Bill Quesinberry of Denver got tired of dealing with people's stares and answering questions. At first, he "hid out at home."

"It was becoming so difficult to get around that it just wasn't worth the effort," he says of a period about three

years ago. "I got tired of people coming up to me and asking if they could help me - because I couldn't figure out what they could help me with. I just got tired of dealing with people looking at me, so it was easier to stay home and avoid them."

His withdrawal was short-lived. During that time of protecting himself from others, he reflected on his situation and, drawing on a lifelong well of self-confidence, developed a new attitude. AFOs and a scooter helped him get around with less difficulty.

"I just decided that I have a great life now. I live in a gorgeous place with gorgeous views. I go to the theater, we go out to dinner. I love the volunteer work I do," Quesinberry, 64, says. "I just decided, I never cared what they thought before. Why should I care now? I realize that people can react to me, and that's fine."

Ramona Hopkins learned in 1986 that she had CMT, after experiencing muscle weakness since childhood. She'd enjoyed bicycling, swimming, softball, hiking and camping, but eventually had to give up each of these activities.

"A couple of years ago, I said, you know, my whole life has been a giveaway, I've had to give that away, I've had to give this away, going through kind of a range of things," she says.

For Hopkins, who lives in Charlotte, N.C., loss isn't always a literal loss of ability. Her CMT can bring on extreme fatigue or muscle pain in response to physical exertion such as walking. "It's a real psychological adjustment to know that you can do this or you can do that - you can do anything you want to if you're willing to pay the price for it."

For example, "I've had to consciously struggle to not swim when I get in the water. I float. I can get out in the water, I can kind of bop along a little bit to get that weightless feeling, which feels good to the muscles. But I've learned consciously not to swim. Don't kick your feet, don't move your arms.

"If I'm going to enjoy being in the water, which is something that I truly enjoy, this is the only way you are going to be able to do it."

In 1998, she became unable to walk because of a spinal disk problem, which led to bone fusion surgery. The pain was largely relieved, but during the months of recovery, she experienced more muscle deterioration. "I didn't know what else I could give up except for my job," she says. "I had this horrible, horrible feeling of helplessness and hopelessness. I had never gone through those feelings before. I had no clue how to deal with it."

Hopkins, 48, saw a psychotherapist who advised her to keep a journal. At all hours, Hopkins would write her thoughts and feelings, never rereading or editing, just getting the thoughts out in words. The experience was eye-opening.

"It wasn't just fear and the hopelessness and helplessness I was feeling from my physical condition," Hopkins says. "It was every emotion I think had bottled up in my brain for one reason or another for years." In her writing, she described fears and other emotions going back to age 4. "Sometimes I would be so mad and angry that I would just be pounding on that keyboard and my head would hurt and my fingers would hurt. Other times I would just be sobbing, other times I would be laughing, other times it would be so automatic you would think I was sleep walking."

After a few months, Hopkins felt she'd worked through most of the pent-up emotions of her life, and was ready to face the new crisis in her physical ability.

"I wasn't going to be able to work, but I had gotten a lot of things worked out. I had gotten past that what-am-I-going-to-do into the this-is-what-I'm-going-to-do stage."

### **4 Know Your Coping Style & Be Kind to Yourself**

Many people who experience a series of losses have a coping style they can draw on.

Lindsey developed a way of anticipating a loss and the solution to it. When a depression would warn her that some loss was occurring, she'd "take steps to make some changes in the environment or recognize what was going on. I'd face it

head on and say, is there some aid that's available, something that I can buy or look into to take care of it?"

That approach, of anticipating what she'll need next - a cane, a scooter, a different schedule - helps her accept the loss and adjust her life.

Hopkins recognizes when her emotions are becoming too difficult to manage.

"Whenever I would get to a point where I would come up with a new emotion, a new fear, a new frustration, a new helpless feeling, something that I had not experienced before, eventually I would go into some type of counseling." Besides a problem-solving coping style, it also helps to have some self-nurturing techniques.

Social worker Coker asks people to make lists of things they enjoy doing or that make them happy. You should make the list at a time when you feel good and things are going well.

Then when you start to feel discouraged or overwhelmed by loss, get your list out and do one of the things on it to make yourself feel better.

"There's a tendency when you're feeling down to not do anything and that just makes it worse," Coker says.

"If you take some sort of action, it gets you out of just sitting there and thinking about all that you don't have. To stay isolated and think about what you don't have anymore just feeds into depression and gets you deeper down and makes it harder to take action."

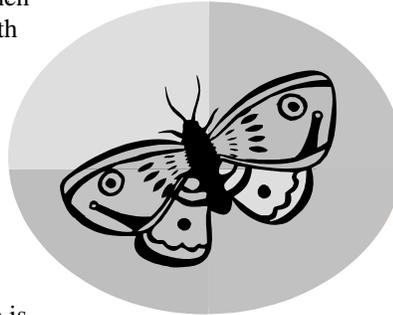
A feel-good action can be as simple as "opening up all of the windows on a nice day and letting the breeze blow through. Going to get a manicure, seeing a movie, or going to a park and just being around nature." Other nurturing actions might include writing your feelings in a journal, listening to music, swimming, playing with pets or doing creative artwork.

Another approach is to keep a gratitude journal and record at least one thing you can be grateful for each day, Coker suggests.

"Maybe it was getting to watch the sunset. It forces people to think about the things

that they do have in their life, rather than what they don't have. There's something very real about focusing on simplicity and surrounding yourself with beauty."

Self-nurturing when you're coping with loss "could get you out of feeling sorry for yourself. It could get you focusing on the things that you do have, the positives. No one is going to nurture you like you can nurture yourself."



## 5 Get Whatever Help You Need

Counseling or support groups help some people cope with loss. Sometimes, getting the right medical care or orthopedic equipment makes a difference.

About six years ago, Wade Kiner of Mitchell, S.D., lost a job for economic reasons. Shortly after that, his walking seriously deteriorated because of Becker muscular dystrophy. He fought using a wheelchair as long as possible, and, when he began using the chair, he felt he'd lost a great deal.

"You're afraid that it will make you more of a shut-in, harder to get out and about," Kiner says. "I spent so much time at home before we actually got the motorized chair, I would be kind of stuck at home. I didn't have any way to get anywhere without some help."

Though staying home provided a needed rest from a fatiguing job, it created financial problems for Kiner's family.

"That was a haul there. You really didn't even feel employable. 'I'm in this wheelchair, what can I do?' I wasn't trained to do anything. It was pretty low right in there."

In 1998, the Kiners were able to get a van with a wheelchair lift and a power wheelchair. "That kind of brought me back to life. That's kind of got me up and mobile and able to work again.

"Once I had the chair, I was just cruising around, going out to the kids' ball games in the summer. It improved our life immensely," he says, adding that it improved his spirits, too.

Coker advises those coping with loss to avoid isolation. Though some time spent in quiet reflection may help you gather your strength, this period should be temporary.

"Sometimes when people try to isolate themselves and deal with it on their own, they don't get information. And that sometimes limits your options," Coker says.

"Depression can also set in. Sometimes that's very hard to get out of if you don't have anybody who can kind of work with you and teach you new ways to cope. It just builds on itself if you refuse to go out there and seek help."

Several people in this article have experienced levels of depression triggered by loss that called for medication. In most cases, a temporary round of antidepressants helped them regain the energy and will to keep going.

But beware of "self-medicating" with excess amounts of alcohol, food, television, Internet cruising or other forms of escape.

## 6 Notice Your Gains & Positive Changes

If you lose an activity, sometimes you can replace it with another that gives you many of the same benefits. In his early 20s, Kiner had to give up bowling, which also meant getting out of touch with some longtime friends. But Kiner, now 37, took up throwing darts, and found "it kind of kept me with the crowd I was in or at least some of them."

Quesinberry finds his life is different, but not his interests and activities.

"I haven't developed any new interests," he says. "I've always loved to read, write, listen to music. I volunteered years before CMT. So nothing has changed that

drastically, except that my world is in slow motion. That's the way I look at it. I don't do anything rapidly any more."

You can't "replace" a significant loss - a person, a relationship, a major ability. But you can reconstruct your life so that the loss is no longer center stage. Both Marlatt and Kiner were faced with the loss of their roles as family breadwinners. But the change brought some rewards.

After Marlatt stopped working as a bank branch manager, his wife started a decorating business out of their home. He worked with her, doing mailings, bookkeeping and things he called "menial." But the activity helped him to feel productive.

Having more time for his two daughters also helped him cope with his losses.

"There were times when I was very resentful of my life. 'My God, why me?' type things when you'd get depressed, particularly if you take a fall," he recalls.

"If I was bummed out, suddenly at 3:15 the kids would come home from the school bus and they're all excited and they're jumping around and making a snack and turning on TV and we're talking about what's going to happen on 'General Hospital' or something. There was always some excitement with them in the house." Marlatt also took over more parenting responsibilities, helping get the girls ready for school in the morning and driving them to activities.

His specially built chair in the family room became the center of family life - the place for socializing and eating meals.

Kiner noticed a similar result. "I got to be with my kids when they were smaller. I guess I got to see them grow up."

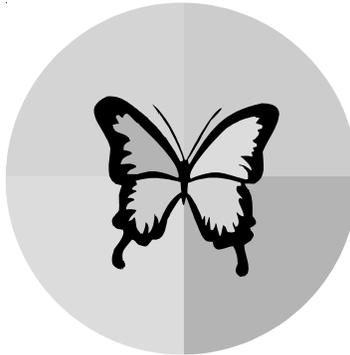
## 7 Realize The Process Isn't Smooth

The popular view of grief as a series of stages - denial, anger, depression, bargaining and acceptance - oversimplifies what is for most people a lifetime of constant adjustment. Stages don't always go in the same order, and new losses may reawaken the pain of old

losses. Larger losses produce deeper grief and take longer to recover from.

Marlatt and his family created a good life after he stopped working, adding equipment and adapting their house as his LGMD progressed. Then his wife was found to have cancer, and she died at age 50.

Around the time of her illness, Marlatt was losing his ability to walk. At about



age 60, he was faced with increasing disability and loss of the person he'd relied on most for help. During that period, he underwent some depression, but has largely bounced back.

Within a couple of years, he'd sold the family business and the home and moved into a seniors' facility, which has independent apartments as well as assisted living and a nursing home. The new residential arrangement has made for a smoother relationship with his daughters and opened up some new social activities. Marlatt, 66, still has some down moments when he contemplates his losses, past and future. But all in all, he copes by dealing with one change at a time.

Grief can be triggered unexpectedly by anniversaries, holidays and other reminders.

This can happen, Coker notes, when you're put in a different environment on the job or at home. "Or you see a picture of yourself from a certain period of time, or somebody sees you for the first time since you've been diagnosed and their reaction to you sends you back."

When such reminders awaken the sense of loss, call on your best coping and self-nurturing techniques.

## 8 Use What You Have Learned to Help Others

Quesinberry and Lindsey put their losses to constructive use by channeling what they've learned to help others.

Quesinberry is very active in his MDA support group and contributes to keeping the conversation "positive."

"I enjoy making other people feel better about whatever. When you respond positively to everything that's going on, it seems like all of a sudden everyone in the group is coming out with positive things."

For example, when people begin to dwell on the fact that there's no cure for their disease or any way to stop its progression, he'll say, "This requires you to be creative. How can I improve what I'm going through? How can I make it easier for me to accept what I'm going through? Rather than, all is doom.

"The thing I ask is: 'Other than physical problems, are you really any different now than you were before? I know I'm not, and I'm pretty sure you're not either.'"

Lindsey, 75, lives in a retirement community in which many people are dealing with physical disability and loss for the first time. Though she's very fatigued by the end of the day, she gets around on her scooter and participates in many activities.

"I feel like the rest of the world is catching up with me," she remarks. "In other words, I slowed down at an early age physically. And now, living here in this retirement community, I don't feel so unique in my limitations.

"I feel that I've used this to help other people, help them cope with whatever their problems are. I was a co-facilitator for an ALS group of caregivers. Being able to do that sort of thing has helped me realize that I'm not useless.

"I like to think of myself as a role model. There's something to be gained."

*Reprinted with permission from QUEST  
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# THE ATTIC

*Occasionally I run into someone who seems genuinely interested in hearing what it is like to live with a relentlessly progressive, unbeatable disease such as ALS. I wrote this for one such friend several years ago. Even though my disability has progressed, my emotional responses have changed very little over the years. Other people with ALS may find it a confirmation of what they have experienced and caregivers and friends might find something worthwhile in it too.*

*BE FOREWARNED: This is not a happy, uplifting message and therefore may not be suitable for people who are having a bum day to start with!*

## THE ATTIC

I thought maybe it was time to take you on a tour of my attic. I don't usually take people up there, but sometimes I meet someone who really seems to want to know what my life is like, and the attic is a good place to start. It tells a story of what has happened to me. The story isn't so much about knowing I am going to die as about having to go on living until I do. It is about being handicapped but it has nothing to do with handicapped parking spaces or accessible bathrooms. Those are just inconveniences. The attic is all about losses.

Ready? Watch your head - the door frame is low and the stairs come up under a low roof! Boy, I need to get John up here to stack some of this stuff, it is really piling up. He is so busy now days that when he has to put something away, he just sets it anywhere. I brought a magic marker so we can at least label these boxes while we are up here ...

Here is the box I sent up when I retired. Nursing books, the old coffee mug, lab coat, name tag: "D. H. \_\_\_\_\_, RN, CNRN, Neuroscience Clinical Education Coordinator." Man, I was so relieved to be free of the physical demands of working! Accomplishing only 2 or 3 hours work in an 8 hour day. Frustrated by projects that I thought would really improve nursing care on the Neuro Unit but simply couldn't physically carry out. Losing touch with the reality of the nurses work because it was changing over time and I couldn't pitch in and do any of it. Whew, I don't miss the frustration and exhaustion! I sure miss the people I worked with though. They call and invite me out to unit parties sometimes, but after a year and a half, those calls are getting infrequent. And I miss me. The neuro nursing expert the staff came to when a patient was in trouble, a family upset, a doctor on the rampage. Someone who taught new nurses what they never learned about neuro in school. A productive (if somewhat irreverent at times) committee member. A respected, well paid professional. That is who I was for 10 years! Label that box "Identity 11/11/95"

Look at this mess! A box of arts and craft supplies. Yarn and paint and woodburning tools. The pattern for the booties I was going to make for my first grandchild. The cross stitch sampler for my daughter's wedding that I had to give up on finishing. Crochet hooks for the set of Christmas Angel tree ornaments I was going make for each of the girls. And a whole stack of woodworking magazines. The bookmarks for all the projects I wanted to try are still in place! I always thought someday I would have the time for this stuff — just like someday I would get serious about getting in shape and someday we would build our own house and someday we would go to Hawaii and someday I would organize my closets and someday I would take some classes just for fun not for a degree. Seems like I just got past the stage of saying "When I grow up, I want to . . ." and now there is no tomorrow, not one that holds any of those things anyway. The feeling that gives me is not really sadness or depression - I am really quite happy on a day to day basis - it is a simple lack of interest in something just isn't going to affect me. The last year that I was working I found myself "dis-engaging," taking on only short term projects, disinterested in improving my management skills, not really caring about the hospital's long term goals. Now I feel that way about life in general. It isn't a crying kind of sad feeling, just kind of an empty one. Label that box "All my Tomorrows."

Whoa, this one is old! There is wallpaper and paint in here from the original owners of this house. This stuff has been replaced and its replacement replaced! Throw that out, but save these rolls. These are what is in the bedrooms now and something might need patched. Goodness knows it is going to have to last a long time. John hates doing this kind of stuff. The current decor of this house is here to stay no matter how outdated it gets or how sick of it I get! It is all John can do to keep up with the laundry, he doesn't have time for redecorating and we sure can't afford to hire it done. Besides, he just doesn't care about decorating. He doesn't notice if the towels match or any of that. He runs strictly on practicality. If you use a certain frying pan regularly, you don't put it away, you put it back on the range. If that ugly, dirty, green throw pillow is comfortable, it belongs on the couch even if it doesn't match a damn thing in the room. Things like that drive me nuts. I seem to have an over-developed sense of color coordination! But, since he does all the work around here and I can't even get to half the rooms in the house, in a practical sense the house belongs to him now. It isn't really mine anymore. Even the family room where I spend 16 hours a day isn't mine. MY room would be neat and clean! I was never a fanatic housekeeper, but now I am really uncomfortable in a room that dirty and cluttered. I guess that discomfort is more because I can't do much about it, not the mess itself. I try hard not to nag about housework, weighing my need for food, drink, bathroom, repositioning, etc. against the fingernails on the chalkboard kind of feeling

that stack of newspapers and junk mail and pizza crusts accumulating on the end table gives me. Gotta prioritize and ration out requests for help or risk mutiny among the galley slaves! Label that box "Environmental Control."

This whole box of clothes really should just go to Goodwill. I don't wear dresses or shorts anymore. My legs get too cold and they look awful anyway. Those long coats and sweaters area nuisance in a wheel chair - you have to stand up to put them on. I wear clothes that are easy to get on and off, are comfortable sitting down, and don't need ironing. Fashion is not an issue! No - that doesn't really bother me. I never was big on fashion or particular about clothes. But it is kind of like the thing with the house - It is all for convenience and practicality, not self expression. I have to wear my hair in a style that John can blow dry quickly and easily. I stopped changing earrings to match my outfits because that was just one more thing John had to do every morning. I was never a fashion fanatic, but I just don't have choices about how I look anymore. Hell, I don't have choices about much of anything. I get up in the morning at 5:30 am because if I don't, I am stuck in bed until someone can get home again to get me up. I eat whatever someone is willing to fix whenever they have time to fix it. When we go out I eat whatever is easier, neater, to eat. Plain hot dogs instead of chili dogs. I go to the bathroom when someone is around to take me. I go shopping when someone has time to drive me. I guess we can label this one "Freedom of Choice."

Now here is an archeological find! My wedding dress is in this box! Do you suppose this will ever be in style again? The last hoop skirt in captivity! Well, my daughters laugh at the dress, but I tell them it could have been worse. It was 1969 and I could have been married barefoot in a meadow wearing nothing but love beads and flowers! Here is the veil and the garter . . . invitation . . . guest book . . . Just close that box, I don't want to see anymore. Yeah, we are still married. I still have John but it doesn't seem like we have a marriage sometimes. It is more of an arrangement held together out of financial necessity and duty. There have been some big stresses on the marriage in the last few years but we seem to be able to handle the big things. It is the loss of the little stuff that hurts. Like holding hands — try going for a walk and holding hands with someone in a wheelchair. Like standing at the sink doing dishes and having him come up behind me and put his arms around me and cop a feel while he talks to me. Like working side by side on the yardwork or cleaning the house or waxing the car. Now I just hang around and watch him work. My contribution is a suggestion or two which, coming from a spectator, are not particularly appreciated. We can still have sex, but it is diminished by not only my physical limitations but also by the fact that he has to take care of me. Try feeling amorous about a really out of shape body you have to bathe and shampoo and dress and undress

everyday. (If that isn't enough to dampen your enthusiasm, try shaving someone's armpits, helping with their tampax and other basics of hygiene and see if you are still interested!) For all that physical intimacy, we seem to be growing further apart. We never had a lot of interests in common. Classic male/female roles. He was into biking and boating and golf and I liked to read and sew and putter around the house. Now I cannot join him in his activities and he has no interest at all in mine. I can't help with the workload of running a household. And I don't even feel entitled to a say in some of the decisions in our lives. I am not going to be here long term and he has to be allowed to plan for a future without me. Yes, I still have a husband who loves me enough to stay in spite of it all, but we aren't really partners, playmates, or lovers anymore. So what the heck do we label this one? Let's call it "My Kind of Love."

Hmm, what is in this box? Oh!! No, don't look! Here, give me the tape. This one is stuff that is not for anyone else to see. No, I don't have any deep, dark secrets! It's just stuff I don't want to have to explain. I don't have much privacy in my life now, so I am keeping my past to myself. I don't mean just physical privacy. It IS an invasion of privacy to have to have someone else dress you, help you to the bathroom, and all that, but it isn't so much what people see as what they know. I can't hide a stash of chocolate, try smoking pot, spend money, buy a present, try a new hairdo, read a book, change my clothes, or put a tape in the VCR without somebody knowing. 99% of the time it is no big deal, but I would like to be able to read "Final Exit" without anyone knowing, re-watch the Beatles Anthology without my family wondering if I have crossed that thin line between fan and pathetic nutcase, and toss out a whole stack of misprinted pages from the computer without anyone knowing I screwed up! There, it is sealed shut. Just label it "Privacy."

Well, enough of this. Stashed away up in this attic is my identity, all my tomorrows, my control over my own home, my freedom to make choices and come and go as I please and when I please, my ideas of the marriage and kind of love I hoped to have, and my privacy. All lost to ALS. Someone in the ALS group once remarked that the ongoing nature of the losses is what makes ALS so hard to deal with. It isn't like an auto accident where you come out paralyzed. That is a huge loss to adapt to, but people do adapt and go on with their lives. With ALS you no more than adapt to the loss of one function when you find you are losing yet another. Losing the physical ability is only the tip of the iceberg. You lose so much more. The attic gets more and more crowded.

Thanks for listening.

*To learn more about the author visit her website at <http://home.att.net/~liveletdie5/ALS/home.html>*

## Helping Yourself Live When You Are Dying

You have learned that you are dying. Terminal illness presents human beings with an exceedingly difficult and contradictory challenge: you are dying, you know you are dying, yet it is your nature to want to live. The thoughts in this article are intended to help you deal with this tension and to continue to live even though you are dying.

### Acknowledging You Are Dying

Acknowledging you are dying is the first step to living the rest of your life. If the onset of your illness was sudden or unexpected, you will likely feel shock and numbness at first. This is a natural and necessary response to painful news. You can only cope with this new reality in doses. You will first come to understand it in your head, and only over time will you come to understand it with your heart.

To acknowledge you are dying is to let go of the future. It is to live only in the present. There is no easy way to do this, and you will probably struggle with this task every day until you die. Know that if you work at acknowledging the reality of your coming death, however, instead of denying it, you will open your heart and mind to the possibility of a new, rich way of living.

### Questioning the Meaning of Life

Discovering that you are dying naturally makes you take inventory of your life. You have a right to have questions, fears and hopes. Illness establishes new directions and often causes some questioning of old directions. New thoughts, feelings and action patterns will emerge. The unknown invites you to question and search for the meaning of your life, in the past, present and future.

### Accept Your Response to the Illness

Each person responds to news of terminal illness in his or her unique way. You, too, will have your own response, be it fear, excitement, anger, loss, grief, denial, hope or any combination of emotions. Becoming aware of how you respond right now is to discover how you will live with your terminal illness. Don't let others prescribe how you feel; find people who encourage you to teach them how you feel. After all, there is no right or wrong way for you to think and feel.

### Respect Your Own Need for Talk, for Silence

You may find that you don't want to talk about your illness at all. Or you may find that you want to talk about it with some people, but not with others. In general, open and honest communication is a good idea. When you make your thoughts and feelings known, you are more likely to receive the kind of care and companionship you feel will be most helpful to you. But if you don't want to talk about your illness, don't force yourself. Perhaps you will be able to open up more later on, after you have lived with the reality of your illness for a time.

### Telling Your Family and Friends You Are Dying

Your family and closest friends deserve to know that you are dying. Tell them when you feel able to. If you simply cannot bring yourself to tell them, find a compassionate person with whom you can entrust this important task.

Be aware that everyone will react differently to your news, just as each terminally ill person reacts differently to his or her own illness. Many will be shocked. Many will cry. Some will refuse to believe it. Some will spring into helpful action by running errands for you, offering to clean your house, etc. Many will not know how to respond. Because they don't know what to say or do, or because your illness may arouse their own fears of mortality, they may even avoid you altogether. Know that their apparent abandonment does not mean they don't love you.

Even children deserve to be told. As with all people, children can cope with what they know. They cannot cope with what they don't know. Be honest with them as you explain the situation in language they will understand. Don't over explain, but do answer any questions they may have.

### Be an Active Participant in your Medical Care

Many people are taught as "patients" to be passive recipients of the care provided by medical experts. But don't forget—this is your body, your life. Don't fail to ask questions that are important to your emotional and physical well-being out of fear that you will be "taking up someone's time."

Learn about your illness. Visit your local library and consult the medical reference books. Request information from educational associations, such as the National Cancer Institute or the American Heart

Association. Ask your doctor, nurses and other caregivers whenever you have a question. If you educate yourself about the illness and its probable course, you will better understand what is happening to you. You will be better equipped to advocate for personalized, compassionate care. You may not be in control of your illness, but you can and should be in control of your care.

### **Be Tolerant of Your Physical and Emotional Limits**

Your illness will almost surely leave you feeling fatigued. Your ability to think clearly and make decisions may be impaired. And your low energy level may naturally slow you down. Respect what your body and mind are telling you. Nurture yourself. Get enough rest. Eat balanced meals. Lighten your schedule as much as possible.

Say Goodbye

Knowing you will die offers you a special privilege: the privilege to say goodbye to those you love. When you feel you are ready, consider how you will say goodbye. You might set aside a time to talk to each person individually. Or, if you are physically up for it, you might have a gathering for friends and family. Other ways of saying goodbye include writing letters, creating videotapes and passing along keepsakes. Whatever their forms, your survivors will cherish forever your heartfelt goodbyes.

### **Find Hope**

When people are seriously ill, we tend to get caught up in statistics and averages: How soon will the illness progress? How long do I have left? These can be helpful to know, but they don't always provide spiritual and emotional comfort.

Even if you are certain to die from this illness, you can find hope in your tomorrows, your next visit from someone loved, your spirituality. At bottom, hope means finding meaning in life—whether that life will last five more days, five more months or five more years.

### **Embrace Your Spirituality**

If faith is part of your life, express it in ways that seem appropriate to you. You may find comfort and hope in reading spiritual texts, attending religious services or praying. Allow yourself to be around people who understand and support your religious beliefs. If you are angry at God because of your illness, realize that this is a normal and natural response. Find someone to talk to who won't be critical of whatever thoughts and feelings you need to explore.

Reach Out for Support

Many of us grew up believing, "Do it on your own so you don't have to depend on anyone else." But confronting a terminal illness cannot and should not be done alone. As difficult as it may be for you, you must reach out to your fellow human beings. Most of us know who we feel comfortable turning to when we are under stress. Whom do you turn to? Give yourself permission to reach out for prayers, support and practical assistance.

Hospices are an indispensable resource for you. They are well-staffed and trained to help both the dying person and the dying person's family. Their mission is to help the dying die with comfort, dignity and love, and to help survivors cope both before and after the death. They often offer support groups for people with life-threatening illness. You might also consider seeing a counselor one-on-one.

Whatever you do, don't isolate yourself and withdraw from people who love you.

*About the Author*

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*Dr. Wolfelt is known internationally for his outstanding work in the areas of adult and childhood grief. Among his publications are the books *Healing the Bereaved Child* and *Understanding Your Grief: 10 Essential Touchstones for Finding Hope and Healing Your Heart*.*

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<http://www.centerforloss.com/pg/HelpingOthersArticles.asp?Function=ShowArticle&Article=Helping%20Yourself-Dying.htm&AudienceID=5>

# Confronting One's Own Mortality

By Betty Scharf, RN

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*"Dying is one thing we know for certain and refuse to believe." ~Jim Boulden*

Years ago a film was made and it was called, *What's It All About Alfie?* This title has stuck with me, and occasionally I begin (or end) my day with it. Eli (PALS) and I spent time yesterday talking about the meaning of life. Somehow when we get around to facing death, the meaning of our lives becomes the main focus. Eli tells me he spends hours each day in deep meditation and contemplation about the meaning of life and death. What do you think is the meaning of life and death? Along the path of life, some persons have told me they know, and I am always in awe of their knowledge and confidence.

As human beings, we alone in this living world are able to contemplate our own death. You have been told you are dealing with a terminal illness, and this offers you the unique opportunity to come to some understanding about who you are, how you have lived your life, and how you want to be remembered. Do you think you have experienced the full joy of being? I don't know your answers and sometimes I am concerned that many of us don't know the questions to ask ourselves. My awareness has been greatly enhanced by the writings of Jim Boulden. I highly recommend his workbook called *"Life Before Death."* (Editor's note, 2007: *This workbook is currently out of print.*)

In the quietness of night, we all have times when we wonder, When? What will it be like? Will I be uncomfortable? Almost everyone wants to ask me these questions when they start confronting their own mortality. These are questions for which I have a few answers. As a nurse, I have stood at the bedside of many persons as they have let go, and said good-bye to this world. It is always a very moving experience. The following examples are usually how people are when they die with ALS.

Perhaps two out of ten persons simply die in their sleep. Often the caregiver will say, I checked him/her less than an hour ago. I never heard anything. For the caregiver there is a sense of discomfort that they were not there to say a last good-bye.

Perhaps four of the ten will fall asleep and drift into a semi-comatose state where they will arouse sleepily for a few seconds when you speak to them. It becomes more difficult to arouse them from this coma as minutes or hours pass. Eventually the respirations become further apart until they cease. This experience of death appears to have no pain, no discomfort and is very peaceful when it is

not interrupted by medical treatment. It gives the family the wonderful opportunity to gather around the bedside and say a last good-bye and express last words of love.

Perhaps three persons of the ten will have breathing that looks as if they are working hard to inspire air. It is more tiring than really uncomfortable for them. After a time of hours, or even a day or so, they drift into a coma. They may or may not need some sedation. This can easily be handled at home under the care of hospice or your physician. I highly recommend the use of a good, well-organized hospice service for approximately the last six months of life. Your physician can order this for you if you make him aware of your wishes. Any well qualified medical person can usually alert you to the signs of the end stages of ALS.

Perhaps one person of the ten will be uncomfortable with shallow respirations, shortness of breath and inability to handle secretions. This situation usually is connected to some sort of respiratory infection and requires medication, sedation and suctioning. With proper treatment, no one should have to suffer at the end of life. This takes planning and fairly quick action by the caregiver. This is the situation where pre-planning is vital. A Do-Not Resuscitate armband is important as well as a Durable Power of Attorney. Hospital care may be appropriate if hospice is not available.

Peace and serenity comes toward the end of life when one has given time to meditation, contemplation, study and reading about life and death. The right questions have been asked and one believes they know their own unique right answers. Confronting our own mortality gives us the freedom to go on with our lives and experience our beingness in new heightened awareness and joy.

Article reprinted from *Reaching Out*, Orange County ALS Chapter, July-August, 1994.

## **The Stages of Dying**

People pass through clearly defined stages in reconciling themselves to death, according to Dr. Elizabeth Kubler-Ross. A psychiatrist who has led the way to a deeper understanding of the needs of dying people, Dr. Ross describes these stages in her book, "On Death and Dying":

**Denial** "No, not me." This is a typical reaction when a patient learns that he or she is terminally ill. Denial, says Dr. Ross, is important and necessary. It helps cushion the impact of the patient's awareness that death is inevitable.

**Rage and Anger** "Why me?" The patient resents the fact that others will remain healthy and alive while he or she must die. God is a special target for anger, since He is regarded as imposing, arbitrarily, the death sentence. To those who are shocked at her claim that such anger is not only permissible, but inevitable, Dr. Ross replies, "God can take it."

**Bargaining** "Yes me, but..." Patients accept the fact of death but strike bargains for more time. Mostly they bargain with God—"even people who never talked with God before." They promise to be good or to do something in exchange for another week, or month, or year of life. Notes Dr. Ross: "What they promise is totally irrelevant, because they don't keep their promises, anyway."

**Depression** "Yes, me." First, the person mourns past losses, things not done, wrongs committed. But then he or she enters a state of "preparatory grief," getting ready for the arrival of death. The patient grows quiet, doesn't want visitors. "When a dying patient doesn't want to see you any more," says Dr. Ross, "this is a sign he has finished his unfinished business with you, and it is a blessing. He can now let go peacefully."

**Acceptance** "My time is very close now and it's all right." Dr. Ross describes this final stage as "not a happy stage, but neither is it unhappy. It's devoid of feelings but it's not resignation, it's really victory."

Excerpted from Christopher News Notes, 12 East 48 Street, New York, NY 10017

*Editor's Note: Since the publication of Dr. Elizabeth Kubler-Ross' first book, many experts in thanatology (the study of death issues) believe they have greater understanding of the reconciliation process of those who are dying. While people facing their own death can move through the various stages of dying, as described by Kubler-Ross, they may skip steps or move through certain stages more quickly than others. These stages now serve as more of a point of awareness for those attempting to understand their own impending death.*

*Note that it may be comforting to understand that your feelings of anger, bargaining, depression, etc., are normal, natural responses to your situation. Also note, however, that these stages do not prescribe how you should be reacting, but simply how you may be reacting. No one should expect you to be reacting in a certain way or rush you through a certain emotion or reaction. These reactions are coping skills that help you move toward finding your own peace and reconciliation with your situation.*

## What is Advance Care Planning?

Advance care planning is making decisions about the care you would want to receive if you happen to become unable to speak for yourself. These are your decisions to make, regardless of what you choose for your care, and the decisions are based on your personal values, preferences, and discussions with your loved ones. A part of advance care planning is also communicating your wishes with your loved ones and healthcare providers to provide guidance and comfort to them if something should happen to you.

### **Advance care planning includes:**

- Getting information on the types of life-sustaining treatments that are available.
- Deciding what types of treatment you would or would not want, should you be diagnosed with a life-limiting illness.
- Getting information on how your disease will progress if you have a life-limiting illness.
- Discussing with your doctor what your treatments are expected to accomplish and what the risks of these treatments are.
- Sharing your personal values with your loved ones. Your spiritual values and beliefs make up who you are and may determine which procedures you want – or do not want.
- Using advance directives to put into writing what types of treatments you would want if you are no longer able to speak for yourself.

## What Are Advance Directives?

The term advance directive describes two types of legal documents that enable you to plan for and communicate your end-of-life wishes in the event that you are unable to communicate:

- A **living will** allows you to document your wishes concerning medical treatments at the end of life.
- A **medical power of attorney** (or health care proxy) allows you to appoint a person you trust as your health care agent (or surrogate decision maker), who is authorized to make medical decisions on your behalf.

Advance directives are legally valid throughout the United States. While you do not need a lawyer to fill out an advance directive, your advance directive becomes legally valid as soon as you sign them in front of the required witnesses. The laws governing advance directives vary from state to state, so it is important to complete and sign advance directives that comply with your state's law. Also, advance directives can have different titles in different states. Before your **Living will** can guide medical decision-making, two physicians must certify:

- You are unable to make medical decisions,
- You are in the medical condition specified in the state's living will law (such as "terminal illness" or "permanent unconsciousness"),
- Other requirements also may apply, depending upon the state.

Before most states' **Medical power of attorney** goes into effect, a person's physician must conclude that they are unable to make their own medical decisions. In addition:

- If a person regains the ability to make decisions, the agent cannot continue to act on the person's behalf.
- Many states have additional requirements that apply only to decisions about life-sustaining medical treatments.
- For example, before your agent can refuse a life-sustaining treatment on your behalf, a second physician may have to confirm your doctor's assessment that you are incapable of making treatment decisions.

## What Else Do I Need to Know?

- Emergency medical technicians cannot honor living wills or medical powers of attorney. Once emergency personnel have been called, they must do what is necessary to stabilize a patient for transfer to a hospital, both from accident sites and from a home or other facility. After a physician fully evaluates the person's condition and determines the underlying conditions, advance directives can be implemented.
- One state's advance directive does not always work in another state. Some states do honor advance directives from another state; others will honor out-of-state advance directives as long as they are similar to the state's own law; and some states do not have an answer to this question. The best solution is if you spend a significant amount of time in more than one state, you should

complete the advance directives for all the states you spend a significant amount of time in. It will be easier to have your advance directives honored if they are the ones with which the medical facility is familiar.

- Advance directives do not expire. An advance directive remains in effect until you change it. If you complete a new advance directive, it invalidates the previous one.
- You should review your advance directives periodically to ensure that they still reflect your wishes. If you want to change anything in an advance directive once you have completed it, you should complete a whole new document.

### **Choosing a Health Care Agent**

A health care agent is someone you designate to make medical decisions for you if, at some future time, you are unable to make decisions yourself. Your agent can be a close relative or a personal friend, but should be someone who knows you well and whom you trust. Your health care agent should be a person who knows your wishes about medical treatment and who is willing to take responsibility to ensure your wishes are followed. In most states, your agent can make decisions any time you lose the ability to make a medical decision, not just decisions about the end of life.

Ideally, your agent should be someone who is not afraid to ask questions of the healthcare professionals in order to get information needed to make decisions. Your agent may need to be assertive to ensure that your wishes are respected. Your agent will need to know as much as possible about your wishes and values regarding the use of medical technology. Not everyone is comfortable accepting this sort of responsibility; therefore, it is very important to have an honest discussion with the person you plan to appoint before you make the appointment.

### **Selecting an Agent**

- Select someone whom you trust and who understands your decisions.
- Because you are asking your agent to accept significant responsibility, be certain to ask your agent if he or she is willing to act on your behalf. Not everyone is able to be an effective agent.
- Talk to your agent about your wishes regarding end-of-life medical treatment. Even family members may not know how much treatment a loved one would be willing to accept near the end of life. Talking clarifies what you want and diminishes an agent's potential guilt and anguish over whether he or she is doing the right thing.
- Prepare and sign the appropriate advance directive forms for your state. Keep the original and give copies to your agent and alternate agents, family, and doctors, and have it placed in your medical record.

### **Benefits of Having an Agent**

- The agent knows you and understands your wishes about medical treatments. He or she can make decisions in situations you might not have anticipated.
- An agent has flexibility. He or she can talk with your physicians about your changing medical condition and authorize treatment or have it withdrawn as circumstances change.
- If you have prepared a living will, your agent can interpret it in situations that were not foreseen. Be sure to make clear in your living will that your agent should make decisions on how to interpret it or when to apply it.
- Your agent can advocate for you. If health care providers resist following your wishes, your agent can negotiate with them and take any other necessary steps to see that your wishes are honored.

### **Advance Care Planning Checklist**

- Get the information you need to make informed choices about end-of-life treatments.
- Discuss your thoughts, concerns and choices with your loved ones.
- Talk to your doctor about different treatments.
- Obtain copies of advance directives (a living will and medical power of attorney) for your state.

- Choose a trusted family member or close friend who is willing to be your advocate if you cannot speak for yourself. Appoint this person as your health care agent.
- Complete the advance directives that follow your state's law.
- Talk to your health care agent, family and doctor about your choices.
- Discuss your choices often, especially when your medical condition changes.
- Keep your completed advance directives in an accessible place.
- Give photocopies of the signed originals to your health care agent, alternate agents, doctor, family, friends, clergy and anyone else who might be involved in your healthcare.
- Encourage your family and loved ones to complete their own advance directives.
- Engage others in discussions about end-of-life care issues and encourage them to complete their own advance directives.
- Get to know end-of-life care services that are available to you such as hospice and palliative care providers. For more information about where to find a hospice or palliative care provider, [click here](#).
- Seek out opportunities to help others who are dealing with end-of-life care issues such as volunteering with a local hospice or end-of-life care coalition. For more information about where to find a hospice or end-of-life care coalition, [click here](#).

For more information about how you can engage others, contact Caring Connections at 800/658-8898 or email, [consumers@nhpco.org](mailto:consumers@nhpco.org).

Excerpted from Caring Connection at [www.caringinfo.org](http://www.caringinfo.org) on March 15, 2007.

## ACTIVITIES FOR PALS

As one faces a terminal illness, such as ALS, it can be rewarding and fulfilling to review one's life journey and reminisce about favorite people, experiences, and events. The following activities are intended to provide suggestions for remembering and reflecting on your life, in order to help you celebrate your successes, cherish your loved ones, and honor your journey. These exercises may also allow you to reconcile or accommodate difficult or painful memories or events, by putting them into the perspective of your history and growth, while providing you with the opportunity to forgive yourself and others as is appropriate.

**Life Review Timeline:** Place the major events of your life on a timeline. You may need several pieces of paper taped together or a large poster board to accommodate the length of your timeline. Measure off periods of time, such as every five or ten years, to give yourself a graph on which to work. Include your successes, special dates, important events, and favorite memories. If you are willing, allow other family members and friends to contribute their memories of you, too. This activity allows you to acknowledge your accomplishments, reflect on troublesome or painful events, and recognize special people or times throughout your life. This timeline, created by you, will also serve as a wonderful keepsake for your family.

**Count Your Blessings:** Make a list of all the things you are thankful for, such as loved ones, friends, special events, honors, successes, abilities, and cherished possessions. Whenever you need a "pick me up," read through your list and reflect on all the things for which you are thankful. Another option is to keep a "Blessings Journal" by writing five things you are thankful for at the end of each day. Some days your lists may look the same; other days you may find new treasures to be thankful for. By focusing and considering all these positive influences, you are celebrating the life you have created and honoring the blessings that have been given to you.

**Messages to Loved Ones:** This activity can take several forms, all of which provide your loved ones with tangible messages from you for the future.

- **Video taped messages:** Have someone video tape you as you record messages to your loved ones, to be viewed at a later date. These messages could be your thoughts and wishes on special occasions, such as birthdays, graduations, or weddings, or they could be general communications that you would like your loved ones to be able to replay and share in the future.

- Cassette recorded messages: You can also record a verbal message, without the visuals of the video, for your loved ones under the same guidelines as above.
- Written letters: Write or type letters to loved ones expressing your thoughts and wishes. You can also dictate your letter to a trusted friend or family member, if you are unable to write. These letters can be sealed and dated to be opened at a time of your designation.
- Readings: Have someone read a video tape you or record your voice on a cassette tape, as you read a child's favorite story, recite a special poem or prayer, or sing a song.

**All About Me**: Answer any or all of the following questions. Consider these queries as starting points for discussing your life, your dreams, your ambitions, and your reflections with your loved ones. Have someone record or write down your responses to create a treasured collection of aspects of your life.

- Who was your best friend in childhood?
- Where did you live when you first moved out of your parents' house on your own?
- Of all the cars you have owned, which was your favorite and why?
- What is your favorite book?
- What is your favorite song?
- What is your favorite movie?
- What is your favorite food?
- How did you meet your spouse?  
Talk about your dating/courtship.  
Who proposed to whom and how?
- What was your first job?  
If you could have been in any occupation, what would it have been and why?  
When you were a child, what did you want to be when you grew up?
- What quality do you think is most important in a friend?
- What is your favorite attribute or ability in yourself?
- What was the scariest moment in your life?
- What was the funniest thing to ever happen to you?
- What was the saddest moment or event in your life?
- What was the most unusual thing that ever happened to you?
- If you were stranded on a desert island, which three things or people would you want to have with you?
- If you could change one thing that you did in your life, what would it be?
- What are you proudest of?

- What is your favorite hobby and why?
- What was your favorite subject in school and why?
- Name three people that influenced your life the most.
- Which teacher had the biggest impact on you and why?
- If your life story was made into a movie, who would portray you?
- If a genie could grant you three wishes, what would they be?
- What is your lucky number?
- Describe your greatest adventure.
- Talk about a time when you were awestruck.
- What was your favorite thing about your mother?  
What was your favorite thing about your father?
- What was the nicest thing someone ever did for you?
- What makes you laugh?
- Name three people that you admire and why.

**Journaling:** Keep a journal of your thoughts, concerns, wishes, and feelings. You can purchase a blank bound journal from the book store, use a simple spiral notebook, or type your journal on the computer. If you want your journal to be private, explain this to loved ones who might have access to it. Make arrangements with a trusted family member or friend to protect the journal after your battle with ALS has ended. Instruct them to either discard or destroy the journal, or allow them to share your entries with selected loved ones of your choice. Journaling can be a cathartic way of expressing emotions and releasing pent up feelings. It can also serve as a process of self-reflection, soul-searching, and life celebration. Don't over think what you are writing; allow your thoughts to flow onto the paper without editing or critiquing yourself. This process will allow you to address issues that are concerning you and work through difficult or unknown problems. It will also allow you to document what is important and meaningful to you.

## WEB RESOURCES FOR PALS

[www.alsa-stl.org](http://www.alsa-stl.org)

The ALS Association, St. Louis Regional Chapter's website provides information about ALS and its symptoms, life management tips, community resource lists, and upcoming chapter events. It also contains information about state and national level advocacy issues, on-going research efforts, and other medical news.

[www.alsa.org](http://www.alsa.org)

The ALS Association National Office website also provides information on public policy, clinical trials, research, and resources. This website contains links to all the ALS Association's regional chapters' websites, each with more localized community content.

<https://als.clinicahealth.com/index.pl>

This website is sponsored by The ALS Association National organization. It provides a chatroom, blogs, and discussions for ALS patients and their families. PALS can meet new friends, find support, and stay informed and involved in ALS issues. This secure site does require registration to enter some areas, which can be completed easily and is free.

<http://www.patientslikeme.com/>

"PatientsLikeMe" is an on-line community dedicated to helping people learn more about ALS, share their stories and experiences with other PALS, and find support from others living with ALS. This chatroom was founded by a family touched by ALS; registration is free.

[www.alsforums.com](http://www.alsforums.com)

"ALS Chat" by ALSforums, is a volunteer resource providing an internet vehicle for information, discussion, and support for anyone affected by ALS. Both PALS and CALS can register for and utilize this free site.

<http://health.groups.yahoo.com/group/living-with-als/>

A mail-list for PALS and CALS, this site describes itself as "an avenue for persons living with ALS and their caregivers to communicate with the ALS community immediately, to share information, ideas, support and fellowship." Membership is free.

[www.helpstartshere.org](http://www.helpstartshere.org)

A website with assistance from social workers. Select "Health & Wellness" on the left side bar, then select "Living With Illness." This section has professional "tips" on talking with children about a loved one's serious illness.

[www.compassionbooks.com](http://www.compassionbooks.com)

This website claims to have over 400 books, videos, and audios for helping children and adults with issues of serious illness, death and dying, grief, and bereavement. Products are written, reviewed, and selected by knowledgeable professionals.

[www.hospicefoundation.org](http://www.hospicefoundation.org)

The Hospice Foundation's website provides information and education for those who are coping with terminal illness, death, or grief.

[www.agingwithdignity.org](http://www.agingwithdignity.org)

The "Five Wishes" document website "provides you with the practical information, advice and legal tools you need to ensure your wishes and those of your loved ones will be respected" with concern to end-of-life issues. Links to other end of life planning sites are included.

[www.caringinfo.org](http://www.caringinfo.org)

Caring Connections is a program of the National Hospice and Palliative Care Organization (NHPCO). This site provides access to information and resources to help make decisions about end-of-life care and services before a crisis occurs. This site has downloadable advance directives by state, including Illinois' and Missouri's.

[www.dyingwell.org](http://www.dyingwell.org)

Ira Byock, M.D., the author of the book, "Dying Well," provides this website for those facing life-threatening illness and their families. His site shares resources, links to pertinent websites, and additional information about end-of-life issues.

By Beth Barrett, MSW  
Patient Services Coordinator  
The ALS Association, St. Louis Regional Chapter  
3/2007

## **BOOKS FOR PALS**

### **Books dealing with ALS**

*Tuesdays with Morrie: An Old Man, A Young Man, and Life's Greatest Lesson*, by Mitch Albom; Broadway, 2002.

*I Choose To Live: A Journey Through Life with ALS*, by William Sinton; Banbury Publishing Company, 2002.

*I Remember Running: The Year I Got Everything I Ever Wanted and ALS*, by Darcy Wakefield; Marlowe & Company, 2006.

*If Only They could Hear Me: A collection of personal stories about ALS and the families that have been affected*, by Ed Rice; BookSurge Publishing, 2005.

*Tales for the Bed: A Memoir*, Jennifer Estess as told to Valerie Estess; Washington Square Press, 2004.

### **Books dealing with end-of-life issues**

*Dying Well*, by Ira Byock, M.D.; Riverhead Trade, 1998.

*The Four Things That Matter Most: A Book About Living*, by Ira Byock, M.D.; Free Press, 2004

*Handbook for Mortals: Guidance for People Facing Serious Illness*, by Joanne Lynn and Joan Harrold; Oxford University Press, USA; New Ed edition, 2001.

*What Dying People Want: Practical Wisdom for the End of Life*, by David Kuhl, M.D.; PublicAffairs, 2003.

# *Legacy of Hope*

## **The ALS Association Lou Gehrig Society ~ St. Louis Regional Chapter**

On July 4, 1939, Lou Gehrig Day was held at Yankee Stadium. That day the world learned of a disease that would take the legendary "Iron Horse" out of baseball forever. His speech touched everyone who heard it. The speech revealed the iron will of a man who embraced his future with courage, integrity, humility, and proclaimed himself "the luckiest man on the face of the earth". Gehrig who died on June 2, 1941, called his Amyotrophic Lateral Sclerosis disease "a bad break," and said he had a lot to live for. In many ways his legacy lives on through his bravery and heroism, and is the inspiration for The ALS Association St. Louis Regional Chapter's Planned Giving program, donors to which exhibit the qualities that Gehrig demonstrated throughout his life. This program is called the ***Lou Gehrig Society - St. Louis Regional Chapter***.

There are many options for making charitable gifts to The ALS Association, St. Louis Regional Chapter. This paper outlines some of the arrangements available to you.

<b>If your goal is....</b>	<b>Explore This Gift Option:</b>
<b>Simple to establish</b>	Simple Bequest Beneficiary Designation Charitable Gift Annuity Gift of Appreciated Stock
<b>Income Tax Deduction</b>	Gift of Appreciated Stock Gift of Real Estate Charitable Gift Annuity Charitable Remainder Trust
<b>Generate an Income Stream</b>	Charitable Gift Annuity Charitable Remainder Trust
<b>Wealth Transfer</b>	Charitable Remainder Trust Charitable Lead Trust
<b>Fastest to Benefit Chapter</b>	Gift of Appreciated Stock Gift of Real Estate

## HOW TO GIVE:

- **Simple Bequest:** A gift that is specified in your will or living trust. Can be for a specific amount, a percentage of your estate, or for the “residue” of your estate after all other bequests have been paid. Can be changed at any time during lifetime. Can be undesignated or restricted for a specific purpose.
- **Beneficiary Designation:** Name the Chapter as a beneficiary of a life insurance policy, your retirement assets, or a pay-on-death account such as a checking or savings account. Avoids probate and is simple to establish, requiring a “Change of Beneficiary” form. Can be changed at any time during lifetime.
- **Charitable Gift Annuity:** A contractual arrangement between a donor and The ALS Association in which a donor transfers assets to The Association in exchange for a fixed income stream for life, part of which is tax-free. When the annuitant(s) pass on, the remainder goes to the Chapter. Can benefit a donor and/or donor’s spouse, or other loved ones. Provides a charitable income tax deduction. If appreciated assets are donated, capital gains can be deferred. Cannot be changed once established.
- **Charitable Remainder Trust:** An arrangement whereby a donor transfers appreciated assets into a trust. The trust pays income to the donor and/or spouse, or to loved ones. At the end of the term, the remainder is paid to one or more charitable organizations such as The ALS Association. Income payments can be fixed or variable. Provides a charitable income tax deduction. If appreciated assets are donated, capital gains can be deferred. Similar to a charitable gift annuity but provides more flexibility for donors. Cannot be changed once established, but donor can retain the right to substitute the charitable beneficiaries.
- **Charitable Lead Trust:** An arrangement whereby a donor transfers assets into a trust. The trust pays income to one or more charitable organizations. At the end of the trust term, the assets either revert back to the donor or are transferred to named heirs. A powerful tool for wealth transfer. Cannot be changed once established, but donor can retain the right to name or substitute the charitable beneficiaries.

## WHAT TO GIVE:

- **Cash:** The simplest asset to give. Also provides the maximum tax deduction.
- **Securities:** Can be transferred directly or used to fund an income-producing gift arrangement. Generally, donors can deduct the fair market value of appreciated securities. Capital gains can be avoided (in the case of an outright gift) or deferred (in the case of an income-producing gift arrangement).
- **Real Estate:** Can be transferred directly or used to fund an income-producing gift arrangement. Generally requires property to be paid off. Generally, donors can deduct the fair market value of appreciated real estate. Older donors can retain the right to live in their home through an arrangement known as a **retained life estate**, for which they receive an income tax deduction.
- **Retirement Assets:** These assets are generally subject to income tax when left to heirs and can also be subject to estate tax. Ideal for charitable giving, which avoids all taxes.

Charitable organizations can be named beneficiaries of retirement accounts. Generally not ideal for lifetime giving (due to taxation), except as noted below:

- **Life Insurance:** Can potentially produce a large gift for little money. Donors can transfer paid-up policies to charitable organizations and receive a tax deduction. Donors can also transfer policies for which premiums are still being paid; an income tax deduction is received as premiums are paid. Charitable organizations can be named beneficiaries of life insurance policies. Life insurance can also be used to replace assets transferred to charitable remainder trusts.
- **Other Assets:** Business interests, partnership interests, personal property, and intangible assets may also be considered for charitable giving, but the tax consequences make these assets less ideal for giving away.

**For more information: consult the chapter's development staff or visit the website.**



The ALS Association  
St. Louis Regional Chapter  
2258 Weldon Parkway  
St. Louis, MO 63146

314-432-7257 or 888-873-8539

**[www.alsa-stl.org](http://www.alsa-stl.org)**

*This information is not intended as legal or tax advice; always consult with your legal or tax advisor for more information. Please consult with your legal and/or tax advisors regarding your specific situation.*



# ADULT LOSS AND GRIEF:

Information  
to help you through  
your bereavement process  
after losing someone to  
ALS



# GRIEF IS LIKE A RIVER

*By Cinthia G. Kelley*

My grief is like a river,  
I have to let it flow,  
but I myself determine  
just where the banks will go.

Some days the current takes me  
in waves of guilt and pain,  
but there are always quiet pools  
where I can rest again.

I crash on rocks of anger;  
my faith seems faint indeed,  
but there are other swimmers  
who know that what I need

Are loving hands to hold me  
when the waters are too swift,  
and someone kind to listen  
when I just seem to drift.

Grief's river is a process  
of relinquishing the past.  
By swimming in hope's channels,  
I'll reach the shore at last.



## *A Prayer for the Bereaved*

*Death is nothing at all. I have only slipped away into the next room. I am I, and you are you. Whatever we were to each other, that we still are. Call me by my old familiar name, speak to me in the easy way which you always used. Put no difference in your tone, wear no forced air of solemnity or sorrow. Laugh as we always laughed at the little jokes we enjoyed together. Let my name be ever the household work that it always was, let it be spoken without effort, without the trace of a shadow on it. Life means all that it ever meant. It is the same as it ever was; there is unbroken continuity. Why should I be out of mind because I am out of sight? I am waiting for you, for an interval, somewhere very near, just round the corner.  
All is well.*

*~Henry Scott Holland  
Canon of St. Paul's Cathedral 1884-1911*

## **WHAT IS GRIEF?**

Grief is a personal, introspective, and active process that varies from person to person. Your relationship to the deceased, your experiences with past losses and death, your personality, and your support system of friends and family can all influence your journey through grief. Know that there is no “right” way to grieve nor is there a timeline for how long one should grieve. Your bereavement process is as individualized as ALS was for your loved one.

Grief is the internal experience of loss. Those emotions and thoughts you have within yourself comprise your grief. Mourning is the term for the outward expression of your grief. The tears, the physical drain, and the rituals you may participate in all represent your mourning. While you may face your grief alone and at a personal level, you can mourn with others who also are grieving. Bereavement is the process and the period of time you take to work through your grief and express it through mourning.

To help you on your grief journey, the following section provides education and information about grief and the bereavement process. By recognizing different aspects of your grief, by creating positive and cathartic mourning practices, and by seeking support and assistance as you need it, may you find personal growth, strength from those who care, and hope for the future.

# The Mourner's Bill of Rights

by Alan D. Wolfelt, Ph.D.

Though you should reach out to others as you do the work of mourning, you should not feel obligated to accept the unhelpful responses you may receive from some people. You are the one who is grieving, and as such, you have certain "rights" no one should try to take away from you.

The following list is intended both to empower you to heal and to decide how others can and cannot help. This is not to discourage you from reaching out to others for help, but rather to assist you in distinguishing useful responses from hurtful ones.

**1. You have the right to experience your own unique grief.**

No one else will grieve in exactly the same way you do. So, when you turn to others for help, don't allow them to tell what you should or should not be feeling.

**2. You have the right to talk about your grief.**

Talking about your grief will help you heal. Seek out others who will allow you to talk as much as you want, as often as you want, about your grief. If at times you don't feel like talking, you also have the right to be silent.

**3. You have the right to feel a multitude of emotions.**

Confusion, disorientation, fear, guilt and relief are just a few of the emotions you might feel as part of your grief journey. Others may try to tell you that feeling angry, for example, is wrong. Don't take these judgmental responses to heart. Instead, find listeners who will accept your feelings without condition.

**4. You have the right to be tolerant of your physical and emotional limits.**

Your feelings of loss and sadness will probably leave you feeling fatigued. Respect what your body and mind are telling you. Get daily rest. Eat balanced meals. And don't allow others to push you into doing things you don't feel ready to do.

**5. You have the right to experience "griefbursts."**

Sometimes, out of nowhere, a powerful surge of grief may overcome you. This can be frightening, but is normal and natural. Find someone who understands and will let you talk it out.

**6. You have the right to make use of ritual.**

The funeral ritual does more than acknowledge the death of someone loved. It helps provide you with the support of caring people. More importantly, the funeral is a way for you to mourn. If others tell you the funeral or other healing rituals such as these are silly or unnecessary, don't listen.

**7. You have the right to embrace your spirituality.**

If faith is a part of your life, express it in ways that seem appropriate to you. Allow yourself to be around people who understand and support your religious beliefs. If you feel angry at God, find someone to talk with who won't be critical of your feelings of hurt and abandonment.

**8. You have the right to search for meaning.**

You may find yourself asking, "Why did he or she die? Why this way? Why now?" Some of your questions may have answers, but some may not. And watch out for the clichéd responses some people may give you. Comments like, "It was God's will" or "Think of what you have to be thankful for" are not helpful and you do not have to accept them.

**9. You have the right to treasure your memories.**

Memories are one of the best legacies that exist after the death of someone loved. You will always remember. Instead of ignoring your memories, find others with whom you can share them.

**10. You have the right to move toward your grief and heal.**

Reconciling your grief will not happen quickly. Remember, grief is a process, not an event. Be patient and tolerant with yourself and avoid people who are impatient and intolerant with you. Neither you nor those around you must forget that the death of someone loved changes your life forever.

Retrieved on 2/13/07 from

[www.centerforloss.com/pg/HelpingOthersArticles.asp?Function=ShowArticle&Article=billofrights.htm](http://www.centerforloss.com/pg/HelpingOthersArticles.asp?Function=ShowArticle&Article=billofrights.htm)

## **MAKING PEACE WITH GRIEF**

*"There will never be another now-  
I'll make the most of today.  
There will never be another me-  
I'll make the most of myself."*

Bob Deits, author of Life After Loss: A Personal Guide Dealing with Death, Divorce, Job Change and Relocation, (Fisher Books, Tucson, AZ 85719, 602-3255-5263, \$7.95), keeps this quotation right over his desk. "It's a good motto for doing effective grief work," he says. "The only time you have to start working through your losses is today. Tomorrow will not be a better day to face up to the task. The only one who can make the journey through your grief is you. But as you make it, you will discover you are equal to the challenge."

**No Right Form of Grief** - Not all of those who have suffered a loss find themselves overwhelmed by grief. Studies recently reported in "The New York Times" "show a far wider range of normal reaction to a grave loss" than was previously thought. "Elements of the prevailing wisdom that now seem more myth than fact include the idea that 'healthy' grieving includes a period of intense distress or depression shortly after the loss, that failure to have such feelings bodes poorly for psychological adjustment, and that the mourners should get over the loss after a finite period of grieving. Five different studies of widows and widowers found that between a quarter and two-thirds of those who are grieving are not greatly distressed. The absence of extreme distress can be a sign of resilience." Bob Deits agrees that "the last thing any of us needs at such a time is a load of guilt because we aren't responding in the right way!"

**A Way Through Grief** - Live After Loss focuses on ways to help those who are distressed after a loss. Deits is a Methodist minister in Tucson who has been a pastoral counselor for 25 years and conducted grief support groups for eight years. His book is "for doing as much as it is for reading." It offers exercises to help make grief manageable and provides guidelines that can be used to run a 12-session support group.

**"The way out of grief is through it."  
"The very worst kind of grief is yours."**

These are the first two of Deits' "Four Key Facts About Grief Recover." He tells the story of Maggie who, two years after her husband's death, told him that she would never get over it. "Maggie," he said, "you're absolutely right! You could work and strain for 50 years, and you won't get over Roy's death. Neither can you get under it or around it. But, you can always get through it!" One exercise he offers to get through grief is to write a letter beginning "Dear Grief" to tell grief what you are feeling. "As close to 24 hours later, but no less, write a letter from your grief to you. I have seen marvelous healing and growth begin with this simple act," he says. His inventive exercises include ways to deal with being unable to sleep and with staying healthy, and, finally, to saying goodbye to grief and beginning again.

**"Grief is hard work."  
"Effective grief work is not done alone."**

These are the remaining two key facts. Need for support may explain why a study reported in "The Wall Street Journal" found that "men are more vulnerable to depression after a spouse's death than women." Frequently, "when the wife died, the husband not only lost his one intimate confidant but also found himself without much support. Men, it's argued, depend on wives to maintain relationships with adult children, relatives and friends." Deits has found that "men seem to have more difficulty sharing grief experiences." With a little investigation, he believes, men can find other men who share their feelings. But he cautions both men and women that "nobody does grief work perfectly. It is a time of slipping and sliding, of three steps forward and three back, of doing your best and discovering it wasn't enough."

# Shattering Eight Myths About Grief

*advice from Hospice Foundation of America*

In order to effectively cope with loss, and to help others who are struggling, it is important to get past some of the common misconceptions about grief. In discussing grief and bereavement during HFA's National Bereavement Teleconference, Cokie Roberts, of ABC News, commented, "Over time, people learn to live with the loss, but it's not something you get over. The grieving process is a series of ups and downs, and often it's more intense in the early years. The thing that we need to remember is that you never have to like a loss. You just have to learn to accept it and deal with it."

A more accurate understanding of the way grief affects us can facilitate healing.

Myth 1: We only grieve deaths.

Reality: We grieve all losses.

Myth 2: Only family members grieve.

Reality: All who are attached grieve.

Myth 3: Grief is an emotional reaction.

Reality: Grief is manifested in many ways.

Myth 4: Individuals should leave grieving at home.

Reality: We cannot control where we grieve.

Myth 5: We slowly and predictably recover from grief.

Reality: Grief is an uneven process, a roller coaster with no timeline.

Myth 6: Grieving means letting go of the person who died.

Reality: We never fully detach from those who have died.

Myth 7: Grief finally ends.

Reality: Over time most people learn to live with loss.

Myth 8: Grievers are best left alone.

Reality: Grievers need opportunities to share their memories and grief, and to receive support.

*For more information about grief and available resources,  
please contact HFA at 1-800-854-3402,  
[www.hospicefoundation.org](http://www.hospicefoundation.org)*



# Count on Grief

## **Count on grief to increase vulnerability**

Human beings are most comfortable when they are in control of their lives and circumstances. Death represents the ultimate "change in plans." When a loved one dies, our former safety and security no longer seems to exist. Instead, we may experience feelings of helplessness and vulnerability that are frightening, as well as disarming. Yet it is precisely this vulnerability that can break down the walls of resistance to new thought processes and open the way for new perspectives on life in general.

## **Count on grief to create change**

Grieving is a walk through unknown territory. Familiar internal and external stabilities disappear in a whirlwind of changing thoughts, feelings and emotional flux. We are reminded of our pain at odd times and in unexpected ways. Emotions hover near the surface and tears are hard to control. The stress of daily living taxes our protective defenses to the limit. Depression seems to slip in from nowhere and anger erupts without warning. Because grief requires so much emotional energy, our finesse for social game playing is greatly diminished. The bereaved meet the world at a disadvantage, continually surprising themselves and others with unpredictable responses to familiar situations.

## **Count on grief to change social structure**

The bereaved find their social networks changing and transforming around them. Disappointment with family and friends is a common theme. Those we expected to "be there for us" may not be able to meet our needs, and friends we didn't know we had appear out of nowhere to fill the void. As we come to terms with whatever limitations and expectations we have for ourselves, we also become aware of the limitations of others. Not everyone we care about will receive what they need from us while we are grieving. Not everyone who cares about us will be able to fully share our pain.

## **Count on grief to define priorities**

The bereaved often find themselves realigning their goals and objectives. For most of us, nothing is easy taken for granted after the loss of a loved one. We understand that "now" is the only time there is and that tomorrow may never come. Relationships are more precious than ever and we are less comfortable with "unfinished business" relating to those we care about. Because the cares and concerns of our busy lives pale in comparison to our loss, the emphasis on people versus things takes on a far greater meaning.

## **Count of grief to increase spiritual awareness**

The pain of grief prompts spiritual investigation in to both the known and the unknown. Answers we were sure of before are not always satisfying in the context of our present reality. God is questioned and religion is held up for examination. Typically, there are many stages of distancing, moving toward, and moving within old and new spiritual concepts and beliefs. Our struggle for inner peace and unity seizes many priorities. In the majority of cases, our connection to ourselves and the universe becomes far more defined.

## **Count on grief to strengthen compassion**

Grief tears down the boundaries between ourselves and others. Bereavement enhances our humanness and strengthens our ties to the world around us. Our loss is a life changing event; we will never again be the same people we were before our loved one's death. Pain somehow opens us to greater levels of awareness and a greater capacity for compassion and understanding. Bereavement provides the catalyst to become more giving, more loving, and more fully aware.

## **Count on grief to define the past and open doors to the future**

Following the death of a loved one, the world is completely new. The death often becomes a reference point around which we define where we've been and how we structure a path for tomorrow. Grief provides a "crash course" in some of the most profound lessons life has to offer. As bereaved individuals, we find ourselves with fewer answers, but far more insights. In time, we learn there is not loss without gain and no sorrow without joy. As death closes doors behind us, new doors open before us.

*from Bereavement Magazine*

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Retrieved on 2/13/07 from [www.taps.org/grief/counton.aspx](http://www.taps.org/grief/counton.aspx)

## **LEVELS OF LOSS**

Loss can come in many and varied forms as a result of separation, divorce or the death of a spouse. An awareness of these losses can help us in our own healing process, and it also can bolster our ability to “be there for others” as they experience loss.

Dorothy J. Levesque, Director of Ministry with S.D.R.W. Persons for the Catholic Diocese of Providence, R.I., had developed a remarkable list entitled “Levels of Loss Experienced by a Person Who is Bereaved and/or Divorced.”

“It is often difficult for the family and friends of an individual who has recently experienced the loss of a loved one (whether through death or through divorce) to understand why the grieving process lasts so long. Family and friends want to see their loved one be happy and “get on with life.” It is, therefore, important to be aware of the many levels of loss. This awareness may help the grieving person, as well as others who care about this individual, be more patient and more gentle during the time (often at least two to five years) of grief.

- 1. Loss of a Loved One:** This level of loss is very obvious; consequently, many think it is the only level of loss.
- 2. Loss of a Large Chunk of Self:** The part of self that was given to the other person in love; at death or divorce, this part of self seems to be violently wrenched from one’s being.
- 3. Loss of Identity:** Oftentimes, an individual identifies self by the “roles of service” used in a relationship; when the other person is no longer present and the role no longer played, the individual often loses the feeling of wholeness.
- 4. Loss of Self Confidence:** Because a grieving person doesn’t recognize his/her personal wholeness, the feeling of inadequacy of not being able to do anything right is often very strong.
- 5. Loss of Chosen Lifestyle:** Divorce or death forces a person to begin a new way of life; in marrying, a person chooses to be married. Even when, for very good reasons, a person must leave a spouse, the person does not willingly choose to be single again.
- 6. Loss of Security:** Because of the new lifestyle, the grieving person doesn’t know what will happen next or how he/she will emotionally react or respond to what will happen.
- 7. Loss of Feeling Safe:** The grieving person feels exposed to the cold winds of life and feels very vulnerable.
- 8. Loss of Known Family Structure:** Death or divorce instantly changes the composition of a person’s family thus creating another level of adjustment that must be faced.
- 9. Loss of Known Parenting System:** No matter what ages one’s children are, the pressures of parenting shift and new stress is added.
- 10. Loss of the Familiar Manner of Relating to/with Family and Friends:** The interests of the grieving person change and, of course, sadness and anger are often evident; because of this, family and friends frequently do not know how to respond and, therefore, avoid the individual.
- 11. Loss of the Past:** New acquaintances and new friends can be very supportive and accepting, but they do not have a sense of the individual’s past journey—of his/her history.

12. **Loss of the Future:** It is frightening for a person in grief to think ahead; to think of next year or next week; there is a fear that whatever future there is will be as painful as the present moment.
13. **Loss of Direction:** The individual doesn't seem to have a purpose in life any more; nothing seems to matter.
14. **Loss of Dreams:** All plans for the individual spending the rest of their lives with the person they love violently disappear.
15. **Loss of Trust:** Because of the intense levels of loss and deep insecurities, it becomes very difficult for the individual to trust self; trusting anyone else is impossible for a long period of time.
16. **Loss of Sharing With a Loved One:** To many, the spouse was also the best friend—a confidante. Consequently, there is no one to listen to the little nothings (and the big events) of day to day living.
17. **Loss of the Ability to Focus:** The grieving person's entire being is so affected by the loss that it becomes difficult to focus on what seems to be the "non-essentials" of the rest of life.
18. **Loss of the Ability to See Choices:** Since the new lifestyle was not a choice, there is a subconscious feeling that the individual has no control over his/her life.
19. **Loss of the Ability to Make Decisions:** Because of the existing insecurity and lack of self-trust, the individual asks everyone "what should I do?" and then becomes more confused—because everyone gives a different answer.
20. **Loss of Sense of Humor:** When the most important person in one's life is no longer around, nothing seems funny.
21. **Loss of Health:** The strain of the emotional and psychological work often causes physical problems such as nausea, migraine headaches, forming muscle knots, back problems, etc.
22. **Loss of Inner Happiness/Joy:** Because so many individuals look outside of themselves for a source of inner happiness, it takes a long time before an individual is able to recognize God in self as the real source of true Joy.
23. **Loss of Patience with Self:** The grieving person wants to feel better NOW and, therefore, feels inadequate when the feelings of grief last for the normal grieving period of two to five years.

"It is important to note that some individuals may experience some levels of loss that are not mentioned in this list. Some of the levels mentioned may be levels not experienced by an individual. This list is presented as a means of helping the grieving person (as well as the grieving person's friends and relatives) understand why nothing can replace the grieving process—the period of time it takes for the wound of loss to become a scar—for the darkness of grief to become the light of life!"

*For handouts of this copyrighted list, or to request permission to reprint, contact Dorothy J. Levesque, Director, Ministry with S.D.R.W. Persons, 80 St. Mary's Drive, Cranston, RI 02920. Telephone: (401)943-7903.*

# Helping Yourself Heal When Your Spouse Dies

by Alan D. Wolfelt, Ph.D.

Few events in life are as painful as the death of your spouse. You may be uncertain you will survive this overwhelming loss. At times, you may be uncertain you even have the energy or desire to try to heal.

You are beginning a journey that is often frightening, overwhelming and sometimes lonely. This article provides practical suggestions to help you move toward healing in your personal grief experience.

## ◆ Allow Yourself to Mourn

Your husband or wife has died. This was your companion, the person you shared your life with. If right now you are not sure of who you are, and you feel confused, that is appropriate because you have lost a part of yourself.

When you experience the death of someone you love, live with, and depend on, feeling disoriented is natural.

You are now faced with the difficult but important need to mourn. Mourning is the open expression of your thoughts and feelings regarding the death of your spouse. It is an essential part of healing.

## ◆ Recognize Your Grief is Unique

Your grief is unique because no one else had the same relationship you had with your spouse. Your experience will also be influenced by the circumstances surrounding the death, other losses you have experienced, your emotional support system and your cultural and religious background.

As a result, you will grieve in your own special way. Don't try to compare your experience with that of others or to adopt assumptions about just how long your grief should last. Consider taking a "one-day-at-a-time" approach that allows you to grieve at your own pace.

## ◆ Talk Out Your Thought and Feelings

Express your grief openly. When you share your grief outside yourself, healing occurs. Allow yourself to talk about the circumstances of the death, your feelings of loss and loneliness, and the special things you miss about your spouse. Talk about the type of person your husband or wife was, activities that you enjoyed together, and memories that bring both laughter and tears.

Whatever you do, don't ignore your grief. You have been wounded by this loss, and your wound needs to be attended to. Allow yourself to speak from your heart, not just your head. Doing so doesn't mean you are losing control, or going "crazy." It is a normal part of your grief journey.

## ◆ Expect to Feel a Multitude of Emotions

Experiencing the death of your spouse affects your head, heart and spirit, so you may experience a variety of emotions as part of your grief work. It is called work because it takes a great deal of energy and effort to heal. Confusion, disorientation, fear, guilt, relief and anger are just a few of the emotions you may feel. Sometimes these emotions will follow each other within a short period of time. Or they may occur simultaneously.

As strange as some of these emotions may seem, they are normal and healthy. Allow yourself to learn from these feelings. And don't be surprised if out of nowhere you suddenly experience surges of grief, even at the most unexpected times. These grief attacks can be frightening and leave you feeling overwhelmed. They are, however, a natural response to the death of someone loved. Find someone who understands your feelings and will allow you to talk about them.

## ◆ Find a Support System

Reaching out to others and accepting support is often difficult, particularly when you hurt so much. But the most compassionate self-action you can take at this difficult time is to find a support system of caring friends and relatives who will provide the understanding you need. Seek out those persons who will "walk with," not "in front of" or "behind" you in your journey through grief. Find out if there is a support group in your area that you might want to attend. There is no substitute for learning from other persons who have experienced the death of their spouse.

Avoid people who are critical or who try to steal your grief from you. They may tell you "time heals all wounds" or "you will get over it" or "keep your chin up." While these comments may be well-intended, you do not have to accept them. Find those people who encourage you to be yourself and acknowledge your feelings – both happy and sad. You have a right to express your grief; no one has the right to take it away.

◆ **Be Tolerant of Your Physical and Emotional Limits**

Your feelings of loss and sadness will probably leave you fatigued. Your ability to think clearly and make decisions may be impaired. And your low energy level may naturally slow you down. Respect what your body and mind are telling you. Get daily rest. Eat balanced meals. Lighten your schedule as much as possible.

Ask yourself: Am I treating myself better or worse than I would treat a good friend? Am I being too hard on myself? You may think you should be more capable, more in control, and "getting over" your grief. These are inappropriate expectations and may complicate your healing. Think of it this way: caring for yourself doesn't mean feeling sorry for yourself; it means you are using your survival skills.

◆ **Take Your Time With Your Spouse's Personal Belongings**

You, and only you, should decide what is done with your spouse's clothes and personal belongings. Don't force yourself to go through these things until you are ready to. Take your time. Right now you may not have the energy or desire to do anything with them.

Remember that some people may try to measure your healing by how quickly they can get you to do something with these belongings. Don't let them make decisions for you. It isn't hurting anything to leave your spouse's belongings right where they are for now. Odds are, when you have the energy to go through them you will. Again, only you should determine when the time is right for you.

◆ **Be Compassionate With Yourself During Holidays, Anniversaries and Special Occasions**

You will probably find that some days make you miss your spouse more than others. Days and events that held special meaning for you as a couple, such as your birthday, your spouse's birthday, your wedding anniversary or holidays, may be more difficult to go through by yourself.

These events emphasize the absence of your husband or wife. The reawakening of painful emotions may leave you feeling drained. Learn from these feelings and never try to take away the hurt. If you belong to a support group, perhaps you can have a special friend stay in close contact with you during these naturally difficult days.

◆ **Treasure Your Memories**

Memories are one of the best legacies that exist after your spouse dies. Treasure those memories that comfort you, but also explore those that may trouble you. Even difficult memories find healing in expression. Share memories with those who listen well and support you. Recognize that your memories may make you laugh or cry. In either case, they are a lasting part of the relationship you had with a very special person in your life.

You may also find comfort in finding a way to commemorate your spouse's life. If your spouse liked nature, plant a tree you know he or she would have liked. If your spouse liked a certain piece of music, play it often while you embrace some of your favorite memories. Or, you may want to create a memory book of photos that portray your life together as a couple. Remember – healing in grief doesn't mean forgetting your spouse and the life you shared together.

◆ **Embrace Your Spirituality**

If faith is part of your life, express it in ways that seem appropriate to you. Allow yourself to be around people who understand and support your religious beliefs. If you are angry at God because your spouse died, accept this feeling as a normal part of your grief work. Find someone to talk with who won't be critical of whatever thoughts and feelings you need to explore.

You may hear someone say, "With faith, you don't need to grieve." Don't believe it. Having your personal faith does not mean you don't have to talk out and explore your thought and feelings. To deny your grief is to invite problems to build up inside you. Express your faith, but express your grief as well.

◆ **Move Toward Your Grief and Heal**

To restore your capacity to love, you must grieve when your spouse dies. There is no specific point in time that indicates the completion of your grief process. Actually, you don't "get over" grief, you live with it as you choose to go on living.

Remember, grief is a process, not an event. Be patient and tolerant with yourself. Be compassionate with yourself as you work to relinquish old roles and establish new ones. No, your life isn't the same, but you deserve to go on living while always remembering the one you loved.

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# Helping Yourself Heal When Someone Dies

by Alan D. Wolfelt, Ph.D.

## *Someone You Love Has Died*

You are now faced with the difficult, but important, need to mourn. Mourning is the open expression of your thoughts and feelings regarding the death and the person who has died. It is an essential part of healing. You are beginning a journey that is often frightening, painful, overwhelming, and sometimes lonely. This article provides practical suggestions to help you move toward healing in your personal grief experience.

### ◆ **Realize Your Grief is Unique**

Your grief is unique. No one will grieve in exactly the same way. Your experience will be influenced by a variety of factors: the relationship you had with the person who died; the circumstances surrounding the death; your emotional support system; and your cultural and religious background.

As a result of these factors, you will grieve in your own special way. Don't try to compare your experience with that of other people or to adopt assumptions about just how long your grief should last. Consider taking a "one-day-at-a-time" approach that allows you to grieve at your own pace.

### ◆ **Talk About Your Grief**

Express your grief openly. By sharing your grief outside yourself, healing occurs. Ignoring your grief won't make it go away; talking about it often makes you feel better. Allow yourself to speak from your heart, not just your head. Doing so doesn't mean you are losing control, or going "crazy." It is a normal part of your grief journey.

Find caring friends and relatives who will listen without judging. Seek out those persons who will *walk with*, not *in front of*, or *behind* you in your journey through grief. Avoid persons who are critical or who try to steal your grief from you. They may tell you, "keep your chin up," or "carry on," or "be happy." While these comments may be well-intended, you do not have to accept them. You have a right to express your grief; no one has the right to take it away.

### ◆ **Expect to Feel a Multitude of Emotions**

Experiencing loss affects your head, heart, and spirit. So you may experience a variety of emotions as part of your grief work. Confusion, disorganization, fear, guilt, relief, or explosive emotions are just a few of the emotions you may feel. Sometimes these emotions will follow each other within a short period of time. Or they may occur simultaneously.

As strange as some of these emotions may seem they are normal and healthy. Allow yourself to learn from these feelings. And don't be surprised if out of nowhere you suddenly experience surges of grief, even at the most unexpected times. These grief attacks can be frightening and leave you feeling overwhelmed. They are, however, a natural response to the death of someone loved. Find someone who understands your feelings and will allow you to talk about them.

### ◆ **Allow for Numbness**

Feeling dazed or numb when someone dies is often part of your early grief experience. This numbness serves a valuable purpose: it gives your emotions time to catch up with what your mind has told you. This feeling helps create insulation from the reality of the death until you are more able to tolerate what you don't want to believe.

### ◆ **Be Tolerant of Your Physical and Emotional Limits**

Your feelings of loss and sadness will probably leave you fatigued. Your ability to think clearly and make decisions may be impaired. And your low-energy level may naturally slow you down. Respect what your body and mind are telling you. Nurture yourself. Get daily rest. Eat balanced meals. Lighten your schedule as much as possible. Caring for yourself doesn't mean feeling sorry for yourself it means you are using survival skills.

### ◆ **Develop a Support System**

Reaching out to others and accepting support is often difficult, particularly when you hurt so much. But

the most compassionate self-action you can do at this difficult time is to find a support system of caring friends and relatives who will provide the understanding you need. Find those people who encourage you to be yourself and acknowledge your feelings -- both happy and sad.

◆ **Make Use of Ritual**

The funeral ritual does more than acknowledge the death of someone loved. It helps provide you with the support of caring people. Most importantly, the funeral is a way for you to express your grief outside yourself. If you eliminate this ritual, you often set yourself up to repress your feelings, and you cheat everyone who cares of a chance to pay tribute to someone who was, and always will be, loved.

◆ **Embrace Your Spirituality**

If faith is part of your life, express it in ways that seem appropriate to you. Allow yourself to be around people who understand and support your religious beliefs. If you are angry at God because of the death of someone you loved, realize this feeling as a normal part of your grief work. Find someone to talk with who won't be critical of your feelings of hurt and abandonment.

◆ **Allow a Search for Meaning**

You may find yourself asking, "Why did he die? Why this way? Why now?" This search for meaning is often another normal part of the healing process. Some questions have answers. Some do not. Actually, the healing occurs in the opportunity to pose the questions, not necessarily in answering them. Find a supportive friend who will listen responsively as you search for meaning.

◆ **Treasure Your Memories**

Memories are one of the best legacies that exist after someone loved dies. Treasure them. Share them with your family and friends. Recognize that your memories may make you laugh or cry. In either case, they are a lasting part of the relationship that you had with a very special person in your life.

◆ **Move Toward Your Grief and Heal**

The capacity to love requires the necessity to grieve when someone loved dies. You cannot heal unless you openly express your grief. Denying your grief will only make it become more confusing and overwhelming. Embrace your grief and heal.

Reconciling your grief will not happen quickly. Remember, grief is a process, not an event. be patient and tolerant with yourself. Never forget that the death of someone loved changes your life forever. It's not that you won't be happy again. It's simply that you will never be exactly the same as you were before the death.

The experience of grief is powerful. So, too, is your ability to help yourself heal. In doing the work of grieving, you are moving toward a renewed sense of meaning and purpose in your life.

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## **GRIEF RESOURCES FOR ADULTS**

*NOTE: Many hospitals and health centers hold grief support group meetings as a community service. Check with your local hospitals, hospice agencies, funeral homes, or nursing homes to see if support groups are available. Often, these are free of charge. Also consider contacting local therapists, social workers, or counselors for both grief support groups and individual grief counseling.*

### **Missouri Support Groups:**

#### **BJC Hospice:**

Widows and Widowers Support Group (ages 35-65)

[www.bjchospice.org](http://www.bjchospice.org)

Contact: Dale Chavis at 314-872-5050 for information

#### **Grief Share support groups**

[www.griefshare.org](http://www.griefshare.org)

Although designed in a 13-week meeting cycle, each meeting is self-contained, so you do not have to attend every meeting to participate.

Check their website listing for local group contact information; groups often meet in local churches.

#### **Missouri Baptist Medical Center: Sunsets and Stages**

[www.missouribaptistmedicalcenter.org](http://www.missouribaptistmedicalcenter.org)

“Day by Day” – a free adult grief support group.

Contact: 314-997-5057 for information

#### **SSM Healthcare**

[www.ssmhc.com](http://www.ssmhc.com)

Free grief support groups meeting at St. Joseph Hospital, Kirkwood, and DePaul Health Center, Bridgeton.

Contact: 314-SSM-DOCS for information

#### **THEOS for Widowed, Midwest, Inc. (They Help Each Other Spiritually)**

12345 Manchester Road

St. Louis, MO 63131

Contact: Cathy Duke, Executive Director at 314-822-3111 for information

### **Illinois Support Groups:**

#### **Alton Memorial Hospital, Alton, IL**

[www.altonmemorialhospital.org](http://www.altonmemorialhospital.org)

Grief, Change, and Loss support groups.

Contact: 618-463-7117 for information

**Carle Foundation Hospital, Urbana, IL**

[www.carle.com](http://www.carle.com)

“Life After Loss” support group.

Contact: 800-610-5547 for information

**Hospice of Southern Illinois, 27 counties in southern Illinois**

[www.hospice.org](http://www.hospice.org)

“Coping with Grief” educational series, offered free to the community throughout the year.

Contact: 800-233-1708 or 618-235-1703 for information

**Our Lady of the Snows, Belleville, IL**

[www.snows.org](http://www.snows.org)

Support Ministry programs include grief workshops.

Contact: Carol Mueller 618-394-6272

**St. Anthony’s Hospital, Alton, IL**

[www.sahc.org](http://www.sahc.org)

Grief support group, monthly meeting.

Contact: 618-463-5636 for information.

**Websites:**

[www.widownet.org](http://www.widownet.org)

Widownet was “the first online information and self-help resource for, and by, widows and widowers.” It contains information on grief and bereavement, financial concerns, related books, and links to other resources.

[www.groww.com](http://www.groww.com)

This website was created for bereaved persons by bereaved persons. It includes a message board, resource listings and links, inspirational writings, memorial pages, and a chatroom hosted by other grieving individuals.

[www.griefshare.org](http://www.griefshare.org)

Grief Share is a support group program for adults in grief. Find a group near your home by entering your city or area code on this website. The 13-week program incorporates videos, group discussion and support, and use of journaling and workbook self-reflection to assist individuals during the grief process. Sign up for the website’s “A Season of Grief” daily emails, which are sent free to your own email address for 365 days. This site and support group programs are Christian based and meetings are generally held at local churches.

[www.death-dying.com](http://www.death-dying.com)

“Beyond Indigo: Changing the way you feel about grief and loss” is a website created “to provide grief support, products and services to individuals and

companies who assist people who are grieving.” Sections include Caregiving & Illness, Children & Grief, Death & the Spirit, Grief Support, and “Ask the Expert.”

[www.bereavementmag.com](http://www.bereavementmag.com)

Bereavement magazine is available to subscribers only; the subscription form can be completed on-line. The website does offer a free “ememorials” area as well as on-line grief “support group” postings.

## **BOOKS FOR ADULTS**

### **Books dealing with ALS**

*Tuesdays with Morrie: An Old Man, A Young Man, and Life's Greatest Lesson*, by Mitch Albom; Broadway, 2002.

*I Choose To Live: A Journey Through Life with ALS*, by William Sinton; Banbury Publishing Company, 2002.

*I Remember Running: The Year I Got Everything I Ever Wanted and ALS*, by Darcy Wakefield; Marlowe & Company, 2006.

*If Only They Could Hear Me: A collection of personal stories about ALS and the families that have been affected*, by Ed Rice; BookSurge Publishing, 2005.

*Tales for the Bed: A Memoir*, Jennifer Estess as told to Valerie Estess; Washington Square Press, 2004.

### **Books dealing with death and grief**

*Fatherloss: How Sons of All Ages Come to Terms With the Deaths of Their Dads*, by Neil Chethik; Hyperion, 1991.

*Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying*, by Maggie Callanan and Patricia Kelley; Bantam, Reprint edition, 1997.

*Finding Your Way After Your Spouse Dies*, by Marta Felber; Ave Maria Press, 2000.

*Healing and Growing Through Grief*, by Donna O'Toole; Compassion Press, date unknown.

*Healing the Adult Child's Grieving Heart: 100 Practical Ideas After Your Parent Dies*, by Alan D. Wolfelt, Ph.D.; Companion Press, 2002.

*Healing Your Grieving Heart: 100 Practical Ideas*, by Alan D. Wolfelt, Ph.D.; Routledge, 1 edition, 1998.

*How To Go On Living When Someone You Love Dies*, by Teresa A. Rando, Ph.D.; Bantam, Reprint edition, 1991.

*I'm Grieving as Fast as I Can: How Young Widows and Widowers Can Cope and Heal*,  
by Linda Feinberg; New Horizon Press, 1994.

*Motherless Daughters: The Legacy of Loss*, by Hope Edelman; Da Capo Press, (2<sup>nd</sup>  
Edition), April, 2006.

**The Centering Corporation** has numerous books, CD's, and videos dealing with grief, death, and the bereavement process. They can be contacted at [www.centeringcorp.com](http://www.centeringcorp.com) or 1-866-218-0101.

**Compassion Books** claims to have over 400 books, videos, and audios for helping children and adults with issues of serious illness, death and dying, grief, and bereavement. Products are written, reviewed, and selected by knowledgeable professionals. They can be contacted at [www.compassionbooks.com](http://www.compassionbooks.com) or 1-800-970-4220.

By Beth Barrett, MSW  
Patient Services Coordinator  
The ALS Association, St. Louis Regional Chapter  
3/2007

## **ACTIVITIES FOR GRIEFWORK**

When you are in the throes of bereavement, you may feel at a loss for ways to process your feelings and move through your grief. The following activities may offer you ways to identify and express your emotions, allow yourself time to remember and honor your loved one, or just have time to be kind to yourself. Be gentle with yourself and allow time to grieve in whatever manner feels right for you. *If you feel overwhelmed or “stuck” in your grief, you may want to contact a professional counselor or therapist or your clergy to talk with about your feelings.*

- **Take a walk** in a local park or just around the block in your neighborhood.
- Write your feelings, concerns, or memories of your loved one in a **journal**. Do not think too much about what you are writing, but instead just let the words flow onto the paper. Journaling can be quite cathartic and provides you with documentation of where you are and where you have been.
- Create a **scrapbook or photo album** of you, your loved one and your family.
- **Color or draw** a mandala. (see the mandala in this section)
- **Work in your garden**. Getting your hands into soil is often very “grounding.”
- **Write a letter to your loved one**. You can include things you did not get to say before, express your feelings of loss and grief, or reminisce about fond memories.
- **Write a letter to your grief**. Then, a day or so later, write back to yourself from your grief. This exercise is surprisingly helpful.
- Get some **physical exercise**. Activity starts to make you feel like “you” again. It can also be cathartic in expressing pent up emotions.
- **Create a memorial** to your loved one in his/her honor. Plant a tree, put favorite framed photographs together on a table, or make a collage of family memories.
- **Light a candle** in honor of your loved one and take a few minutes of quiet contemplation.
- **Pray**, spend time at your place of worship, or speak with clergy, if it brings you comfort at this time.
- **Join a local grief support group**. Most communities offer this service, which provides connection with and support from others who are also grieving. (see grief resources in this section)
- Visit the **Missouri Botanical Garden** or **Laumeier Park**. These facilities both offer areas for quiet walking and contemplation while enjoying the beauty of nature.

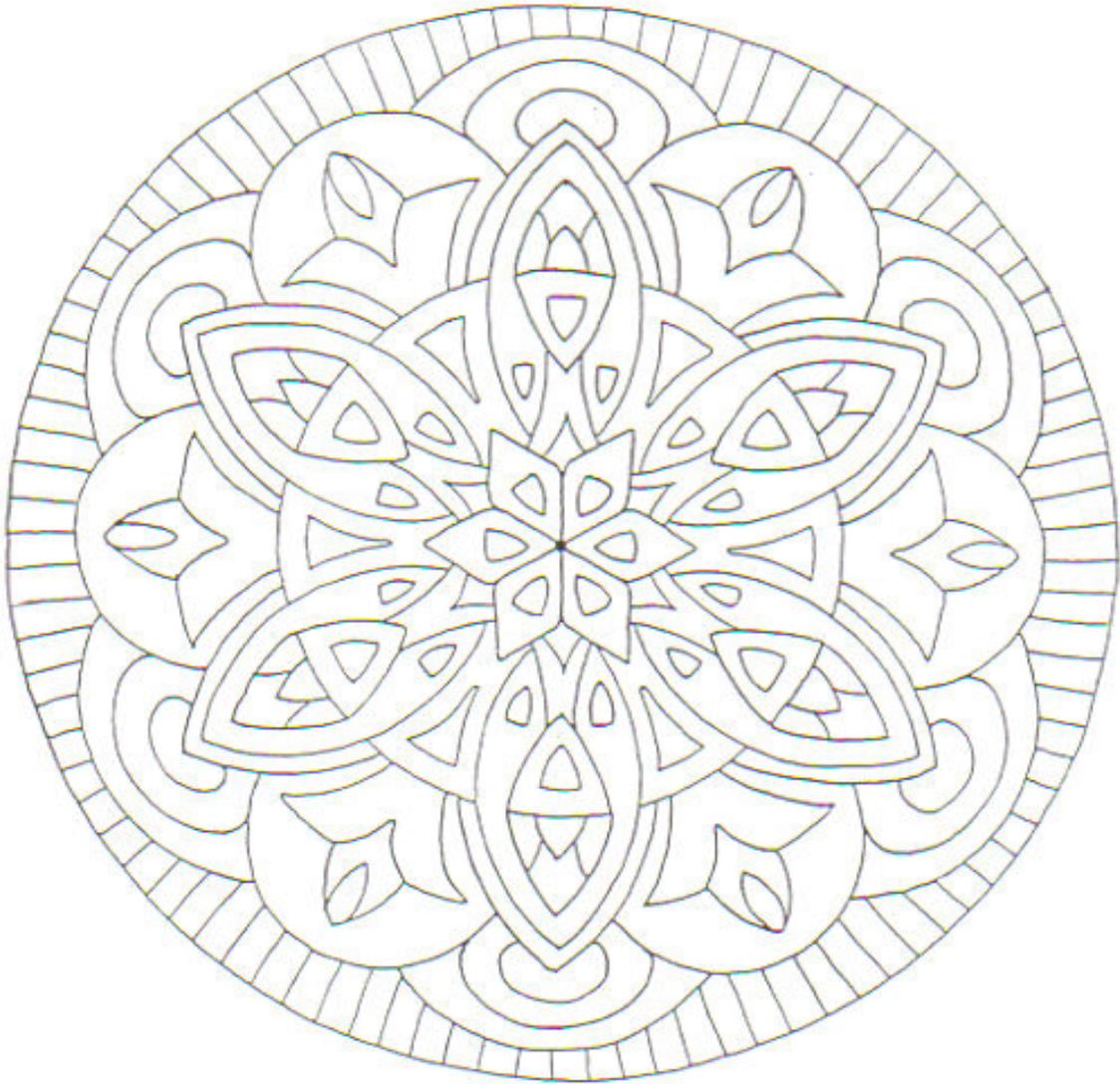
- **Call a friend.** Sometimes our friends and family do not know how to help us through our grief. Don't be afraid to ask others for what you need.
- **Take a nap.** Grieving is hard work and you may become physically tired from it. Allow yourself the luxury of an afternoon catnap.
- **Create a memory box** to hold special tokens and memories of your loved one. Decorate a small wooden box, a small plastic storage box, or a cardboard shoebox. Inside, place pictures, tokens, dried flowers, cut-outs from magazines, a special piece of jewelry or fabric—anything that reminds you of your loved one. Keep this box in a special place in your home.
- Go to the symphony, a local high school concert, or play favorite CD's or tapes. Immerse yourself in the healing **power of music**.
- **Volunteer.** Whether at your local church, food pantry, school, or social service agency, giving of yourself will give you purpose while concentrating on others will help you process your own grief.
- **Meditate, practice yoga, or walk a labyrinth.** Each of these will offer you time for contemplation and quiet reflection.
- **Listen to a guided meditation tape.**
- **Do something every day that gives you pleasure.** Even in grief, you have the right to look forward to something or feel small moments of happiness each day. Your loved one would want you to do this.
- **Let others do things for you.** Don't be afraid to tell others what you need or to ask for assistance. Your friends and family want to help you, but may not know how.
- **Eat healthy, regular meals.** Your body needs support and gentle care while you grieve.
- Allow yourself the luxury of a **bubble bath**. Or consider getting a **massage**. These pampering activities can feel rejuvenating and comforting.
- **Say "No."** Do not feel obligated to take on responsibilities or projects before you are ready. You also do not have to accept every social invitation.
- Be ready to **say "Yes."** Be pro-active in re-engaging yourself into a social life. Don't miss out on life's pleasures because you are consumed in grief. When you are ready, make an effort to again participate in life's activities, responsibilities, and joys.

# MANDALAS

The mandala is a symbolic, circular design used in Tantric Buddhism as a point of concentration. The word "mandala" means "circle" in the Sanskrit language. Mandalas are usually drawn or colored as a type of meditation or calming focus. Since coloring and drawing are action-oriented, the inner dialogue of the mind is disconnected allowing for inner peace or insights to surface.

Mandalas can be incorporated in the practice of self-expression or self-discovery. **Coloring or drawing a mandala lends itself to grief work as a way to disengage the dialogue in one's mind, while allowing feelings and emotions to surface and be expressed through color or design.**

Color the mandala below using colored pencils, markers, or crayons. Make copies of the blank mandala to use again at a later date, if you wish. Feel free to draw your own mandala design; allow yourself to draw freely without critiquing what you are including. Time spent with the mandala is best done alone or in a quiet setting, when you have some time for yourself.



# CHILDREN AND GRIEF:

Information for  
Parents and Caregivers  
of children who are  
grieving

## SEE THIS CHILD

See this child before you  
wounded  
vulnerable  
changed  
...the child of yesterday gone forever.

Who will really look at this child?  
Is it easier to assume  
he will emerge unscathed  
then to face the turmoil with him?

Who will step into the road  
before this child...  
laden with mountains and valleys,  
potholes and detours?

Who will walk a bit of his journey with him?

Who will offer some temporary shelter  
from the storms that rage around  
and within this child?

Who will open doors that this child  
cannot see through his pain?

Who will listen to what this child  
is really saying  
when he is belligerent  
when he is too shy to speak  
when his laughter masks his fears?

Who will help this child to recognize  
his successes,  
and give him the courage to step  
beyond his failures with dignity?

Who will be with this child  
on the other side of healing  
as he recognizes his growth  
and acceptance?

Excerpt from DEATH AND THE CLASSROOM  
Cassini/Rogers, *Griefwork of Cincinnati*,  
~Sister Teresa McIntier, RN, MS

## **How Children Deal with Death and Grief**

Talking with children about dying, death, and grief can be a daunting and frightening experience for adults. While the development of hospice and palliative care is changing the climate, our society still often treats death as a “taboo” subject. As adults, we want to support our children and their emotional needs, but we also want to protect them from negative experiences and spare their feelings when we can. Since death can often be such a painful and upsetting experience, adults tend to withhold or avoid giving information to children about the dying process, the actual death, the funeral or memorial services, and the bereavement process. Adults are also dealing with their own grief, which complicates their abilities to support or share with their children.

Be aware that your child(ren) will be aware of the death and experience grief and the bereavement process whether you talk to him/her or not. Even at a very young age, children can sense the pain and disruption that results from a loved one’s death. Therefore, it is best to talk openly and honestly with children about what death means and how their loved one’s death will affect their future. You want to give them accurate facts about what has happened and what they might experience. You also want to validate their feelings as normal and assure them that they will continue to be care for and loved.

While the grieving process can feel painful, overwhelming, and confusing, not understanding this process can be even more detrimental to both children and adults. By speaking openly with your children and understanding their abilities to comprehend and manage what has happened, you will help them move through the bereavement process with love, support, and a feeling of safety.

Children’s cognitive abilities and emotional coping skills vary according to their ages and personalities. You know best how your child(ren) learns, comprehends, reacts, and copes with new concepts and experiences. The following list provides general guidelines as to how children understand death and dying in each developmental stage. You will want to consider your child’s specific abilities as you help them through their bereavement. Remember, the best thing you can do to support your child at this time is to offer them honest age-appropriate answers, while assuring them that you and other family members will continue to love and care for them through this difficult period.

### **DEVELOPMENTAL STAGES GUIDELINES**

The following guidelines will help you talk to your child using language and concepts that are understandable to his/her age.

#### **Infant to two years old**

Children this age have limited verbal expression and will demonstrate their emotions and discomfort through actions. This age group has no concept of death. They will not understand that a loved one has died, but will sense and react to the emotions of parents and other family members.

##### *Possible Reactions:*

- Fussiness, irritability
- Clinginess

- Tears, vomiting, regression in behavior, such as toileting, sleeping or eating

Suggestions:

- Maintain a regular routine
- Provide nurturance and physical security, such as holding and cuddling with child
- Provide reassurance and patience
- Allow child to play, as this is an outlet for children's grief

### **Three to Five years old**

The pre-schooler is gaining verbal skills and has a strong sense of curiosity. Expect many questions from this age group. They may utilize "magical thinking," such as worrying that something they did or said caused someone's death or believing that death is reversible. This child lives in the present tense; they will not understand the finality of death. They may also begin to personify death as a person or thing, such as a skeleton or angel of death.

Possible Reactions:

- Numerous, repetitive questions; curiosity about death
- May appear unconcerned or show little reaction
- Regression in behavior, such as nightmares, toileting, possible violent play
- Fear of separation

Suggestions:

- Allow questions and talk with child
- Answer questions honestly and in simple words and terms
- Use real terms, such as death or dead, not "sleeping" or "gone away"
- Provide structure and a normal schedule
- Offer patience, explanations, and assurance
- Resist punishment for acting out
- Encourage physical activity and play to express feelings and expend energy
- You may have to clarify that death is not contagious

### **Six to Nine years old**

This age group has developed more cognitive skills and will have a clearer understanding of death. They will begin to understand that they, too, will die some day. (This concept solidifies for older children in this age group.) They have more logical thinking and begin to move away from the magical thinking of earlier years. They may fear death and will begin to be able to mourn. Be aware that while this age group may understand the realities of death, they have not developed sufficient emotional or social skills to deal with their grief. They may need extra attention and support.

Possible Reactions:

- May want details and explanations about death
- Crying; active mourning
- Will be concerned about others' feelings
- Grief expression may come and go
- May appear anxious or emotional; may "act out"

Suggestions:

- Provide reassurance

- Respond to their needs and questions honestly and compassionately
- Allow for creative play through art, stories, etc.
- Encourage physical play as an outlet for grief and energy expression

### **Nine to Twelve years old**

This age group has developed the understanding that death is final. At this age, death becomes personal. These children may focus on the consequences of the death, such as concerns about having to move, changing plans, or not being able to participate in activities due to the death. They may have curiosity about the biological details of death. This group may not talk as much about death or they may try to be “brave” for other family members.

#### **Possible Reactions:**

- Distractedness, denial, guilt, anger
- School work may suffer; grades may fall
- May fear leaving home or parents; separation anxiety
- May put on a “brave face” and not show emotions
- May withdraw or act out

#### **Suggestions:**

- Give permission for expression of feelings
- Encourage child to ask questions and give honest answers
- Avoid punishment, but offer encouragement, reassurance, compassion
- Allow child to NOT be brave by giving them time to express emotions and worries
- Ask if and how this child might like to be involved in the memorial services.
- Remember to give hugs

### **Teenagers**

Teenagers think abstractly and have full understanding of death. They realize the finality of death and understand that everyone will die. While they have feelings of their own immortality, they also realize how fragile life can be. Their thinking is comparable to an adult’s in many ways, but this age group may not have the social support from peers who understand their grief. They may also be experiencing grief for the first time and these intense feelings can be surprising or frightening.

#### **Possible Reactions:**

- Crying, traditional mourning
- Denial or risk taking
- Taking on the adult role; being the “man” or “lady” of the house
- Depression; suicidal thoughts
- Willingness to talk with peers or non-family members about the death
- Change in behavior at school; grades falling

#### **Suggestions:**

- Encourage conversation and expression of grief; be honest
- Allow child to have time to mourn; do *not* expect them to take over the adult role
- Seek out professional help, if needed, such as a school counselor, professional therapist, or clergy

- Utilize teen support group services
- Provide love and support

### **Young Adults (College-age to mid-20's)**

The young adult has full adult thought processing and completely understands the implications of death. This age group is often overlooked when considering children dealing with a death in the family. People assume that this older child can handle the bereavement process like an adult. They forget this young adult child may need attention or support, as he/she may be living out of the household in an apartment, away at college, or in another city. This age group may also not have many peers who have experienced the death of a close loved one, so they may not receive the social support they need.

#### **Possible Reactions:**

- Acting as if everything is fine; denying problems or intense feelings of grief
- Distancing themselves from family situation
- Depression; suicidal thoughts
- Immersing themselves into their work or school responsibilities
- Not taking the time to grieve

#### **Suggestions:**

- Engage in conversation and offer support; talk about the loved one
- Encourage college students to seek assistance from their university's mental health department; most colleges offer counseling to their students for free or minimal costs
- Allow the young adult to grieve at his/her own pace
- Help the young adult identify peers who are understanding and supportive; encourage their interaction with these peers (grief support groups, a friend who has also experienced a death in the family, church young adult groups, etc.)

### **Other considerations for children of all ages:**

- Allow all family members to comfort one another. It is healthy to allow your child to see you actively grieve. Let them offer you their support; share your grief as a family.
- Even young children should be given the option of attending funeral services and/or participating in the arrangements. By early elementary school, children will be able to express whether or not they would like to be involved. Give an honest explanation, in simple terms, of what they might expect to see at the funeral: the casket, people crying, people laughing and sharing happy memories, singing, people speaking about the loved one, etc.
- Do not "force" a child to attend services or look at the body of the deceased. Allow the child to express his/her desire to do so. While viewing of the body allows for closure for some people, this can be quite traumatic for others. Trust the child's judgment as to whether they wish to participate.
- For school-age children, notify the child's school, teachers, and/or counselor. Not only will they be able to make accommodations for the child's absence and make-up work, but they will have a greater understanding of the child's possible behavior changes. School staff can be a wonderful source of support and school

- can provide a sense of routine and “normalcy” for the child. (*see “Helping Children Grieve at School” handout in packet for more information*)
- Realize that children, especially younger ones, may move in and out of their grief. They may cry one minute and be laughing and playing the next. This is normal behavior. Children process grief in smaller “bites” than teenagers and adults. Allow them to process at their own pace.
  - Realize that all the feelings and emotions you, your children, and your family are experiencing as a result of a loved one’s death are NORMAL! No two people will grieve the same way. Everyone may experience a myriad of emotions as they process their grief.
  - Also realize that your family members’ grief may resemble a roller coaster: On a roller coaster the front cars may be at the top of a hill, while the back cars may be down in a valley. The cars are all traveling a similar path, but hit different points at different times. This is the same with your family’s grief experiences. Some of you may be having a bad day, while others are feeling better. The next day, those feelings may reverse. You all may not experience the same emotions at the same time. Be respectful of each other’s individual expressions of grief and do not judge one another as you each move through your bereavement together as a family.
  - If you or a family member continues to have intense feelings of depression or has thoughts of harming themselves or others, seek professional help. While grief is intense, emotional, and disruptive, it does soften as time progresses. Support one another and seek out professional guidance as needed.

Beth S. Barrett, MSW  
Patient Services Coordinator  
The ALS Association, St. Louis Regional Chapter  
February, 2007

# Helping Grieving Children at School

## A Student is Grieving

As a teacher or school counselor, you know how profoundly a student's home life affects her school life. The two are inextricably intertwined. When someone in the child's family dies, then, the death colors every moment of every day for the child. The child cannot "put her grief aside" while she learns and plays alongside the other students. Instead, she must learn to integrate her grief into all aspects of her life, including school.

You can help. By following the guidelines in this article, you will help the child cope with her grief and ease the transition from life before the death to life after the death.

## School is a Place for Support

You are important to your students. From you they learn not only facts and figures, but behaviors and emotions. They also rely on you for support during the seven or so hours they are in your care each day. In many ways, you are not only their teacher or counselor, but their authority figure, role model friend and confidant during the school day.

So, school isn't just a place for book learning. It's a home away from home, a place for students to share their lives with others. When a student is grieving, he needs to share his new and scary feelings. He needs to know that like home, school will be a stable and loving refuge.

## Talking to Children about Death

As a teacher or counselor, you are probably good at talking to children. You know that they respond better, for example, when you get down on their level and maintain eye contact. You ask open-ended questions to solicit their thoughts and feelings. Without talking down to them, you use language that they understand.

Keep up the good work. You'll need all these skills as you help students grieve. But you may find that talking about death isn't so easy. That's OK. Our culture as a whole has a hard time discussing death.

Actually, what grieving children need most is for someone to listen to and understand them—not to talk at them. Instead of worrying about what to say, try to create opportunities for your bereaved student to talk to you about the death.

## Learn About Grief

To help your students cope with death and grief, you must continually enhance your own knowledge of childhood grief. While we will never evolve to a point of knowing "everything there is to know about death," we can always strive to broaden our understanding and degree of helpfulness. Take advantage of resources and training opportunities as they become available.

Another part of learning about grief involves exploring your assumptions about life and death. Think about your own personal losses. Who close to you has died? What did their deaths mean to you? Were you a child when someone you loved died? If so, how did you feel? How did the important adults in your life—including teachers and counselors—help you with your feelings of grief? Thinking about these issues will help you better help your students.

## Teach What You Learn to Students

Don't wait until a student's parents are killed in a car accident to teach your class about death and grief. Make lesson plans that incorporate these important topics into the curriculum. And use natural,

everyday encounters with death—a run-over squirrel, a car accident that made local headlines—to talk about your students’ fears and concerns.

Remember the concepts of the “teachable moment” and “created moment.” The teachable moment occurs when an opportunity to teach children about life and death arises through events happening around them. A baby is born; a classmate's grandfather dies. When these events occur, make positive use of them by talking openly about them. The created moment means not waiting for “one big tell all” about death but working to create regular opportunities to teach children about death.

Children who have already been acquainted with the naturalness and permanence of death are more likely to grieve in healthy ways when someone they love dies.

#### Acting-Out in the Grieving Child

Many children express the pain of grief by acting-out. This behavior usually varies depending on the child's age and developmental level. The child may become unusually loud and noisy, have a temper outburst, start fights with other children, defy authority, or simply rebel against everything. Other examples of acting-out behavior include getting poor grades or assuming a general attitude that says, “I don’t care about anything.” Older children may even run away from home.

Underlying a grieving child’s misbehavior are feelings of insecurity, abandonment and low self-esteem. This basic recognition is the essence of artfully helping during this difficult time. My experience as a grief counselor has shown me that probably the two greatest needs of a bereaved child are for affection and a sense of security. Appropriate limit-setting and discipline, then, should attempt to meet these essential needs. We must let bereaved children know that we care about them despite their present behavior.

Adult modeling and setting reasonable boundaries help bereaved children develop their internal controls while at the same time providing children the opportunity to make painful mistakes. As we all know, discovering we make mistakes as we grow up is an important lesson.

### **Guidelines for Helping Grieving Children**

- Be a good observer. A bereaved child’s behavior can be very telling about her emotions.
- Listen. Let each child teach you what grief is like for him. And don’t rush in with explanations. Usually it’s more helpful to ask exploring questions than to supply cookie-cutter answers.
- Be patient. Children’s grief isn’t typically obvious and immediate.
- Be honest. Don’t lie to children about death. They need to know that it’s permanent and irreversible. Don’t use euphemisms that cloud these facts. Use simple and direct language.
- Be available. Bereaved children need to know that they can count on the adults in their lives to listen to them, support them and love them.

#### About the Author

*Dr. Alan D. Wolfelt is a noted author, educator and practicing clinical thanatologist. He serves as Director of the Center for Loss and Life Transition in Fort Collins, Colorado and is on the faculty at the University of Colorado Medical School in the Department of Family Medicine.*

*As a leading grief counselor and educator, Dr. Wolfelt is known internationally for his outstanding work in the areas of adult and childhood grief. Among his publications are the books *Helping Children Cope with Grief and Understanding Your Grief: 10 Essential Touchstones for Finding Hope and Healing Your Heart*.*

Retrieved on 2/13/07 from

<http://www.centerforloss.com/pg/HelpingOthersArticles.asp?Function=ShowArticle&Article=Helping%20Children%20at%20School.htm&AudienceID=5>



**Lost & Found****417-832-9423**

1201 E. Walnut  
Springfield, MO 65802  
[www.lostandfoundozarks.com](http://www.lostandfoundozarks.com)

“Provides ongoing grief support groups for children 3-18 and their parents or caregivers” at no cost to families. “Lost & Found was modeled after The Dougy Center, an internationally recognized center for grieving children and their families.”

**MISSOURI BEREAVEMENT CAMPS and RETREATS****Camp Courage****314-965-5015**

Annie’s Hope, St. Louis, MO

“Camp Courage is a week long, overnight camp for children and teens, ages 6-18, who are grieving the death of someone significant.” It is held at Garrison Family Campground in Steelville, MO, often in early June. Enrollment is on a first come, first served basis. A contribution to defray expenses is appreciated, but no child is turned away due to inability to pay. Call the office at Annie’s Hope for a camp registration form.

**Labyrinth****314-953-1776**

BJC Hospice, St. Louis, MO

This one day, teen retreat is held twice a year on a Saturday in the spring and fall. This program is for teens, ages 13-18, who have experienced the loss of a significant loved one. Teens will participate in group discussions, hands-on activities, and the opportunity to walk a labyrinth. Contact BJC Hospice and request a registration or more information (including location) from the bereavement department.

**Teen Retreat****314-965-5015**

Annie’s Hope, St. Louis, MO

“The teen retreat is a safe, non-threatening, supportive overnight weekend gathering of teenagers who are grieving the death of someone significant. It starts on Friday at 5:30 p.m. and ends on Sunday around 3:30 p.m.” Approximately 10 teens, ages 13-18, participate with 3-4 adult facilitators. There is no cost for this event. Contact Annie’s Hope for more information, retreat location, and registration forms.

**Stepping Stones Bereavement Camp****314-953-1776 or 314-872-5050**

BJC Hospice, St. Louis, MO

This weekend camp in August is open to children ages 6-12 who have experienced the loss of a loved one within the last year. It is held annually at Camp Wyman in Eureka, MO, and is free of charge. The application process begins in the spring.

## **ILLINOIS SUPPORT GROUPS**

### **The Heartlinks Program**

**618-277-1800**

Family Hospice of Belleville

5110 West Main Street

Belleville, IL 62226

[www.familyhospice.org/heart.htm](http://www.familyhospice.org/heart.htm)

“A community resource available to families with children (newborn to 18) who are experiencing or anticipating a death. The objective of the program is to provide support and fellowship for the children, while equipping parents and caregivers with the necessary tools to understand and help kids experience grief.” Services are provided free of charge; families do *not* have to have been involved with hospice to participate.

### **Hospice of Southern Illinois**

**800-233-1708**

305 South Illinois Street

Belleville, IL 62220

[www.hospice.org](http://www.hospice.org)

This hospice serves 27 counties in southern Illinois. They offer the “Coping with Grief” educational series throughout the year, discussing “grief through a lifetime,” coping with change, and community resources. While this may not be specifically designed for children, it could be helpful for parents of a child in grief. Call for more information and dates.

## **ILLINOIS BEREAVEMENT CAMPS and RETREATS**

### **Camp Courageous**

**309-672-5746**

Methodist Hospice Services, Peoria, IL

This one day camp is free and offered to any child (ages 5-18) in the central Illinois region who is experiencing grief. Activities are facilitated by trained grief counselors and include horseback riding, crafts, and group discussion. This annual event is held at Camp Manitoumi; call to inquire about registration.

### **Camp Healing Heart**

**217-383-3021**

Carle Foundation Hospital, Urbana, IL

A weekend camp is offered free of charge for grieving children, ages 7-17, in the central Illinois area. Sponsored by Carle Hospice, it is held annually at the University of Illinois, 4-H Memorial Camp near Monticello, IL. The weekend involves age-appropriate activities, crafts, nature walks, and facilitated group discussions. Call for information and to register.

### **Kids Count Day Camp**

**800-233-1708**

Hospice of Southern Illinois, Belleville, IL

This free day-camp is for children ages 5-15 who are experiencing grief. An adult must accompany the child for the duration of the day. Adult programming runs concurrently with the children’s activities. This day-camp is open to the community; it is held annually in Belleville and Marion. Registration is required.

## BOOKS FOR CHILDREN

The following books can be used to educate children about ALS or to discuss related issues that arise for children as they cope with living with a loved one who has the ALS diagnosis. Books are grouped by general reading level. However, please be aware that many of these books are considered “classics” for grief issues and are appropriate for all age groups, especially those in the younger reading categories.

### Younger Children

*Badger's Parting Gifts*, by Susan Varley; HarperTrophy, Reprint edition, 1992.

*I Miss You: A First Look At Death*, by Pat Thomas; Barron's Educational Series, 2001.

*I'll Always Love You*, by Hans Wilhelm, Crown Publishing, 1985.

*Lifetimes: The beautiful way to explain death to children*, by Bryan Mellonie, Bantam, 1983.

*Sad Isn't Bad: A Good-Grief Guidebook for Kids Dealing With Loss*, (Elf-Help Books for Kids) by Michaelene Mundy; Abbey Press, 1998.

*The Tenth Good Thing About Barney*, by Judith Viorst; Aladdin Publishing, 1987.

*What's Heaven?*, by Maria Shriver; Golden Books Adult Publishing, 1999.

### Grade-school age Children

*35 Ways to Help a Grieving Child*, by The Dougy Center for Grieving Children & Families; The Dougy Center, 1999.

*Aarvy Aardvark Finds Hope*, by Donna O'Toole; Compassion Books, 1988.

*Healing the Grieving Child's Heart: 100 Practical Ideas for Families, Friends & Caregivers*, by Alan D. Wolfelt, Ph.D.; Companion Press, 2001.

*How It Feels When a Parent Dies*, by Jill Krementz; Peter Smith Publisher, 1993.

*Nana Upstairs & Nana Downstairs*, by Tomie dePaola; Putnam Juvenile, Reissue edition, 2000.

*Tear Soup*, by Pat Schweibert and Chuck DeKlyen; Grief Watch, 3<sup>rd</sup> Revised edition, 2005.

*The Fall of Freddie the Leaf*, by Leo Buscaglia; Holt, Rinehart, & Winston, 1982 or 20<sup>th</sup> Anniversary Edition, Slack Publishing, 2002.

*The Next Place*, by Warren Hansen; Waldman House Press, 1997.

*When Dinosaurs Die: A Guide to Understanding Death*, by Laurie Krasny Brown and Marc Brown; Little, Brown Young Readers, Reprint edition, 1998.

### **Teenagers**

*Fire in My Heart, Ice in My Veins: A Journal for Teenagers Experiencing a Loss*, by Enid Samuel Traisman. Centering Corporation, 1992.

*Griefjourney: Notes of Grief for Teens, Young adults and Anyone Who is Grieving*, by Mark Scrivani. Centering Corporation, 2004.

*Healing Your Grieving Heart for Teens: 100 Practical Ideas, Simple tips for understanding and expressing your grief*, by Alan D. Wolfelt, Ph.D.; Companion Press (CO), 2001.

*Help for the Hard Times: Getting Through Loss*, by Earl Hipp; Hazelden, 1995.

*How It Feels When a Parent Dies*, by Jill Krementz; Peter Smith Publisher, 1993.

*I Will Remember You: What to do when someone you love dies: A Guidebook Through Grief for Teens*, by Laura Dower; Scholastic, Inc., 2001.

*Straight Talk about Death for Teenagers: How to Cope with Losing Someone You Love*, by Earl A. Grollman; Beacon Press, 1993.

*The Grieving Teen: A Guide for Teenagers and Their Friends*, by Helen Fitzgerald; Fireside, 2000.

*The Next Place*, by Warren Hanson; Waldman House Press, 1997.

*You Can Get There From Here: Journaling Through the Grief, a Guide for Teens and Young Adults*, by Leah Hawley; Keuka-Saguro Publishing, 2005.

For additional books on grief, look in the psychological section of the book store or type in "grief" for a search on [www.amazon.com](http://www.amazon.com). Many new and used books can be purchased on Amazon at a reduced price.

Also, two catalogue companies specialize in books and other print resources on grief. Their websites are: [www.compassionbooks.com](http://www.compassionbooks.com) and [www.centering.com](http://www.centering.com).

## GRIEF WEBSITES FOR CHILDREN AND THEIR FAMILIES

[www.annieshope.org](http://www.annieshope.org)

“Annie's Hope-The Bereavement Center for Kids is a community based nonprofit organization whose mission is to provide comprehensive support services for children, teens and their families who are grieving the death of someone significant.” This website provides information about grief education, support groups and camps, upcoming events, a loan library, and opportunities for involvement. Predominantly informational, this site is for adults who are helping grieving children.

[www.kidsaid.com](http://www.kidsaid.com)

“KIDSAID is where kids can come, to get help and to help each other.” This site is part of Griefnet, where anyone can come to get assistance with grief issues. This site offers “kid-2-kid” on-line support group, a kids email Q&A, peer support, stories, poems, games, and artwork, all in a kid-friendly fashion. Information is also available for adults who are assisting children in the grief process.

[www.griefworksbc.com](http://www.griefworksbc.com)

This site provides information and activities in three different categories: You're a Kid if you are 12 and under; You're a Teen if you are 13 and over; and You're an Adult. Each category has age-appropriate activities, educational material, and links to other resources. The K2K on-line support group is for children 18 and younger, who have experienced a loss. Only children may post on this site, which is monitored by trained volunteers under the guidance of a clinical psychologist. Parents must give permission for their children to join the K2K support group.

[www.grievingchild.org](http://www.grievingchild.org)

The Dougy Center for Grieving Children and Families created this website. “The mission of The Dougy Center for Grieving Children is to provide support in a safe place where children, teens and their families grieving a death can share their experiences as they move through their grief process.” This site provides comprehensive information about grief issues and concerns, provides answers to frequently asked questions, and includes a bookstore for grief related products. This center is nationally known and a leader in grief issues, especially for children.



**CHILDREN**  
(ages 12 and under)

*Information  
to help you understand  
your loss and grief*



## ALS and Death

People have ALS in their body only. It doesn't affect the spirit or soul inside them that makes them special and unique. Their spirit and soul is what makes us love them so much. We can't see their spirit or soul, but we can feel it every time they laugh, smile, and cry.

Eventually, everyone's body that has ALS gets tired. When the body is so tired that it can't fight the disease anymore, it dies. The spirit or soul leaves the body and continues to live on somewhere else. Some people believe spirits or souls go to Heaven, while others think that they take a different form -- kind of like a caterpillar turning into a butterfly. We don't really know for sure, but we do know that the spirit of someone we love lives on deep in our hearts every time we remember them.

When someone dies, it leaves an empty space in our hearts and lives. This empty space is called a loss and this loss causes pain called *grief*. When someone we love dies, it is sad. It is okay to cry and ask for help from others that love you. Sometimes when we ask grown-ups for help, we help them too. Helping each other can make our loss and grief seem less scary and painful.



# My Grief Rights: Ten Healing Rights for Grieving Children

by Alan D. Wolfelt, Ph.D.

***Author's note:** This "bill of rights" for grieving children is intended to empower them to help themselves heal—and to help direct the adults in their lives to be supportive as well.*

Someone you love has died. You are probably having many hurtful and scary thoughts and feelings right now. Together those thoughts and feelings are called *grief*, which is a normal (though really difficult) thing everyone goes through after someone they love has died.

The following ten rights will help you understand your grief and eventually feel better about life again. Use the ideas that make sense to you. Post this list on your refrigerator or on your bedroom door or wall. Re-reading it often will help you stay on track as you move toward healing from your loss. You might also ask the grown-ups in your life to read this list so they will remember to help you in the best way they can.

- 1. I have the right to have my own unique feelings about the death.** I may feel mad, sad or lonely. I may feel scared or relieved. I may feel numb or sometimes not anything at all. No one will feel exactly like I do.
- 2. I have the right to talk about my grief whenever I feel like talking.** When I need to talk, I will find someone who will listen to me and love me. When I don't want to talk about it, that's OK, too.
- 3. I have the right to show my feelings of grief in my own way.** When they are hurting, some kids like to play so they'll feel better for awhile. I can play or laugh, too. I might also get mad and scream. This does not mean I am bad, it just means I have scary feelings that I need help with.
- 4. I have the right to need other people to help me with my grief, especially grown-ups who care about me.** Mostly I need them to pay attention to what I am feeling and saying and to love me no matter what.
- 5. I have the right to get upset about normal, everyday problems.** I might feel grumpy and have trouble getting along with others sometimes.
- 6. I have the right to have "griefbursts".** Griefbursts are sudden, unexpected feelings of sadness that just hit me sometimes—even long after the death. These feelings can be very strong and even scary. When this happens, I might feel afraid to be alone.
- 7. I have the right to use my beliefs about my god to help me deal with my feelings of grief.** Praying might make me feel better and somehow closer to the person who died.
- 8. I have the right to try to figure out why the person I loved died.** But it's OK if I don't find an answer. Why questions about life and death are the hardest questions in the world.
- 9. I have the right to think and talk about my memories of the person who died.** Sometimes those memories will be happy and sometimes they might be sad. Either way, these memories help me keep alive my love for the person who died.
- 10. I have the right to move toward and feel my grief and, over time, to heal.** I'll go on to live a happy life, but the life and death of the person who died will always be a part of me. I'll always miss this special person.

## MIXED EMOTIONS

When someone you love has died, you can experience many different emotions. It is important to identify and talk about things that make you uncomfortable, as well as things that make you feel good.

*Complete the following sentences and feel free to share your answers with an adult you trust and who cares about you.*

I feel happy when \_\_\_\_\_.

I feel sad because \_\_\_\_\_.

A favorite memory of my loved one who died is \_\_\_\_\_.

I feel safe when \_\_\_\_\_.

I especially miss \_\_\_\_\_.

My favorite family activity is \_\_\_\_\_.

Sometimes I worry about \_\_\_\_\_.

One thing I like about myself is \_\_\_\_\_.

If I could change one thing in my life, it would be \_\_\_\_\_.

One person that I can talk to is \_\_\_\_\_.

I feel comforted when \_\_\_\_\_.

I am having trouble adjusting to \_\_\_\_\_.

One thing that gives me hope is \_\_\_\_\_.

## Ways to Help Let Your Feelings Out

- Play with your friends.
- Keep a journal and write down how you feel.
- Listen or Dance to Music.
- Draw, color or paint a picture.
- Stuff an old pillowcase with rags and use it as a punching bag.
- Create a memory album about your loved one and/or your family. Draw pictures, write stories or poems, recall memories or favorite activities, or include photographs.
- Hit baseballs in a batting cage.
- Make a memory box honoring your loved one. Decorate a small cardboard or wooden box and put inside small treasures, pictures, magazine cutouts, or everyday items that remind you of your loved one.
- Go for a walk.
- Throw ice cubes in the bathtub.
- Ride your bike, roller skate, roller blade, or run fast.
- Write a letter to a trusted friend, sharing how you feel.
- Talk to a trusted friend or grown-up about your loved one.
- Make a collage with pictures cut from old magazines. Choose pictures that express your feelings or that remind you of favorite family activities with your loved one.
- Shoot hoops with your basketball.
- Tell funny jokes and laugh with friends.
- Play a musical instrument or sing out loud.
- Write a poem about how you feel.
- Use your hands: knit, crochet, do a jigsaw puzzle, etc.
- Spend time in nature. Work in the garden or your yard, take a walk in the park, or go on a hike in the woods.
- Create a new family activity or ritual to honor the memory of your loved one, such as planting a tree, reading a special story or scripture, lighting a candle (with an adult present), or donating your time to a worthy cause.
- Give yourself time to daydream; you don't always have to be busy.

## BOOKS FOR CHILDREN

These books are written especially for children like you, who have had a loved one die. These books deal with loss and grief—how it feels to have someone you love die and ways in which you can cope with those feelings. Ask an adult who loves you to read these books with you or read them on your own. Remember that you have adults who love and care about you; share your concerns, feelings, or questions with them when you are ready.

*Aarvy Aardvark Finds Hope*, by Donna O'Toole; Compassion Books, 1988.

*Always and forever*, by Alan Durant; Harcourt, Inc., 2003.

*Badger's Parting Gifts*, by Susan Varley; HarperTrophy, Reprint edition, 1992.

*How It Feels When a Parent Dies*, by Jill Krementz; Peter Smith Publisher, 1993.

*I Miss You: A First Look At Death*, by Pat Thomas; Barron's Educational Series, 2001.

*I'll Always Love You*, by Hans Wilhelm, Crown Publishing, 1985.

*Lifetimes: The beautiful way to explain death to children*, by Bryan Mellonie, Bantam, 1983.

*Nana Upstairs & Nana Downstairs*, by Tomie dePaola; Putnam Juvenile, Reissue edition, 2000.

*Sad Hug, Mad Hug, Happy Hug: A Children's Story About Death*, Channing L. Bete Company, 1994.

*Sad Isn't Bad: A Good-Grief Guidebook for Kids Dealing With Loss*, (Elf-Help Books for Kids) by Michaelene Mundy; Abbey Press, 1998.

*Tear Soup*, by Pat Schweibert and Chuck DeKlyen; Grief Watch, 3<sup>rd</sup> Revised edition, 2005.

*The Fall of Freddie the Leaf*, by Leo Buscaglia; Holt, Rinehart, & Winston, 1982 or 20<sup>th</sup> Anniversary Edition, Slack Publishing, 2002.

*The Goodbye Boat*, by Mary Joslin; Wm. B. Eerdmans Publishing Company, 1999.

*The Next Place*, by Warren Hansen; Waldman House Press, 1997.

*The Tenth Good Thing About Barney*, by Judith Viorst; Aladdin Publishing, 1987.

*What's Heaven?*, by Maria Shriver; Golden Books Adult Publishing, 1999.

*When Dinosaurs Die: A Guide to Understanding Death*, by Laurie Krasny Brown and Marc Brown; Little, Brown Young Readers, Reprint edition, 1998.

*When I Feel Sad*, by Cornelia Maude Spelman; Albert Whitman & Company, 2002.

## GRIEF WEBSITES FOR CHILDREN AND THEIR FAMILIES

[www.annieshope.org](http://www.annieshope.org)

“Annie's Hope-The Bereavement Center for Kids is a community based nonprofit organization whose mission is to provide comprehensive support services for children, teens and their families who are grieving the death of someone significant.” This website provides information about grief education, support groups and camps, upcoming events, a loan library, and opportunities for involvement. Predominantly informational, this site is for adults who are helping grieving children.

[www.kidsaid.com](http://www.kidsaid.com)

“KIDSAID is where kids can come, to get help and to help each other.” This site is part of Griefnet, where anyone can come to get assistance with grief issues. This site offers “kid-2-kid” on-line support group, a kids email Q&A, peer support, stories, poems, games, and artwork, all in a kid-friendly fashion. Information is also available for adults who are assisting children in the grief process.

[www.griefworksbc.com](http://www.griefworksbc.com)

This site provides information and activities in three different categories: You're a Kid if you are 12 and under; You're a Teen if you are 13 and over; and You're an Adult. Each category has age-appropriate activities, educational material, and links to other resources. The K2K on-line support group is for children 18 and younger, who have experienced a loss. Only children may post on this site, which is monitored by trained volunteers under the guidance of a clinical psychologist. Parents must give permission for their children to join the K2K support group.

[www.grievingchild.org](http://www.grievingchild.org)

The Dougy Center for Grieving Children and Families created this website. “The mission of The Dougy Center for Grieving Children is to provide support in a safe place where children, teens and their families grieving a death can share their experiences as they move through their grief process.” This site provides comprehensive information about grief issues and concerns, provides answers to frequently asked questions, and includes a bookstore for grief related products. This center is nationally known and a leader in grief issues, especially for children.

# TEENAGERS

(ages 13-18):

Information  
to help you through  
your grieving process

*“The pattern of your grief is unique,  
shaped by your particular relationship, specific circumstances,  
and distinctive temperament.  
Ignore others’ attempts to tell you how to feel or how long to feel.”*  
~Karen Katarfiasz

# The Grieving Process

Grief is a natural, normal response to loss. Although grieving the death of someone is a normal reaction, at times grief can feel enormously painful, overwhelming, and exhausting. Beginning to understand your grieving experience, and taking gradual steps to address your pain and loss, can be important and integral components of recovering from your grief.

## Stages of Grief

Within the first few weeks to months after a death, you may find yourself riding on a roller coaster of shifting emotions. Most people go through these stages not in linear steps, but in unpredictable waves—moving through one stage to the next and sometimes shifting back. Some people will also experience certain phases but not others. Here are several common, typical grief reactions:

- **Shock/Disbelief:** This is the numbing, disorienting sense that the death has not really happened, not really occurred. This reaction can be intensified and complicated if the death is sudden, violent, or unanticipated. Your mind may be telling you “there must be some mistake,” or “this can’t be true.” These symptoms typically last from several hours to several days.
- **Anger:** Your anger may be targeted at a number of sources. You may feel waves of anger at the doctors who treated your loved one, anger at your family members for not rallying together, anger at God over what seems senseless or unjust, even anger at yourself or the person who died and “left” you.
- **Guilt:** You may blame yourself for not doing more, not being there enough, or not being there when the death happened. You may feel regret over “unfinished business” – conflicts you and the deceased never resolved, or feelings between the two of you that were never fully discussed or shared.
- **Sadness:** You may experience a deep sense of loss. There may be moments when you find yourself at a loss for words, weeping, or bursting uncontrollably into tears.
- **Fear:** There may be anxiety or panic, or fears about carrying on, fears about the future. If the person who died was an adult (partner, sibling, parent), it may bring up fears about your own sense of mortality or sense of being left behind.
- **Depression:** You may go through periods of melancholy, or “blueness,” where you feel inclined to withdraw or isolate yourself. You may lose interest in your usual activities, or feel helpless or hopeless.

In addition to these stages, people who are grieving frequently experience physical symptoms, such as fatigue, sleep disruption, appetite changes, increased tension, and numerous aches and pains. Grief can also affect you on a psychological level. Some of these common signs include feeling distracted, forgetful, irritable, disoriented, or confused.

### **Tasks of Mourning**

In healthy grieving, the tasks of mourning and completing one's grief come in several stages. The first is to accept and fully experience your loss, including feeling and expressing your pain and sorrow. Second, is to let go of your attachment to your loved one and your accompanying grief. Third, is to start to form new relationships or attachments in your life. This third phase is where you feel you are moving through your healing and recovery, and can start to develop new commitments and ties to people and activities.

Excerpted from University of California Health Services website  
<http://www.uhs.berkeley.edu>

## **BILL OF RIGHTS FOR THE GRIEVING TEEN**

1. You have the right to your own feelings. Others may tell you how you should feel, but they can't possibly know what you are experiencing.
2. You have the right to express your feelings and to expect support for what you are going through.
3. You have the right to be comforted by family and friends even when they do not understand your pain.
4. You have the right to be an integral part of the funeral ritual if you so desire.
5. You have the right to ask questions about your pain and loss and to expect that you will not be deceived or treated as a child.
6. You have the right to be treated as a unique individual.
7. You have the right to be who you are and not be measured by another's standards.
8. You have the right to grieve until you are ready to bring closure to the relationship that was stilled in death.
9. You have the right to expect professional counseling to deal with any guilt that may be real or imagined.
10. You have the right to share your personal journey through the valley of grief in order to be comforted and to comfort others.

# GRIEF

## What Is Grief?

Grief is a natural emotional reaction to a significant loss or expected loss. It is an essential component of the eventual emotional process of recovery from loss. Grief usually occurs in response to many different types of loss, including:

- the death of a loved one
- the end or breakup of a significant relationship
- a loved one experiencing a chronic or terminal illness
- the loss of an important life factor, such as financial security or a job you like
- the death of a pet
- a significant negative change in health or physical functioning

## Grief vs. Mourning

**Grief** is the internal experience of loss; the thoughts and feelings about a loss that you experience within yourself.

**Mourning** is the outward expression of grief. Crying, talking about the person who died, or celebrating memories and anniversary dates are all ways of mourning.

*At times, we must grieve alone, but mourning is also necessary so that you are not alone.*

## When helping people who grieve, it is important that you do **NOT**...

- Withdraw from the survivor, removing your support.
- Suggest positive outcomes from the loss.
- Mention that the death could have been prevented in some way (e.g., If only....).
- Rationalize positive aspects the death.
- Compare the survivor's grief reaction to other people you know.
- Dwell on your own grief to show your sorrow.
- Become frightened by intense emotions and then retreat from the situation.
- Try to talk them out of their feelings.
- Force physical gestures (*i.e., hug, holding hands, etc.*). If unsure, it can be helpful to extend a hand to touch them and if they appear uncomfortable it is best to retreat and offer silent support without touch.
- Take rejection by the survivor as a personal attack on you or your relationship with the survivor.

## Myths about the grief process

**Myth:** *The experience of grief and mourning proceed in predictable and orderly stages, such as denial, anger, guilt etc.*

This stages-of-grief idea is appealing, but inaccurate. It emerged from Elisabeth Kubler-Ross' groundbreaking book, *On Death and Dying*. However, Dr. Kubler-Ross did not intend for these emotions to be interpreted as stages or steps, but rather to help people understand that denial, anger, guilt, and sadness are common, normal and expected reactions. If

you are experiencing anger, it doesn't mean that you are "less evolved" than someone feeling guilt. Many people do not fully experience all of these feelings. Who is to say what is a "normal" feeling for every person when you have lost someone you loved? Find people who accept you and your grief, and who allow you to be where you happen to be in the grieving process.

## "Be Strong"

**Myth:** *After losing someone you love, your goal should be to "be strong", and "get over" your grief as soon as possible. Crying means that you are "falling apart", and that is not what anyone wants.*

Crying is nature's way of releasing tension, and it lets others know that you need to be comforted. When stress is high, crying even discharges accumulating stress toxins within our tears.

Society often encourages people to quickly move away from grief. Unfortunately, refusing to cry, suffering in silence, and "being strong" are often viewed as admirable and desirable reactions to loss. Friends, family, and co-workers may encourage this stance because they don't want to talk about painful things, and there is nothing they can say or do to make it better. Many people have internalized the idea that grieving and mourning should be done quickly, quietly, and efficiently. The message from others seems to be, "Just get over it."

Find someone who accepts that no one can "make it better", and that your life surely will not be the same without the person (or pet) you loved. Find someone who can be present with you while you grieve so you do not have to bear it all alone. In time, you can learn to live with your grief while you learn to adjust to life without the presence of person (pet) who has departed.

## "How long should grief last?"

**Myth:** *It takes between three months and a year to "get over" losing someone you love.*

This question relates directly to our culture's impatience with bereavement and the desire to move people away from the process of mourning as quickly as possible. We expect grieving people to "get back to normal" soon after the death or loss. All too often, we succumb to the myth that grief should be moved away from rather than moved toward, as something to be *overcome*, rather than experienced. Interestingly, when people are allowed to move toward their grief and to mourn openly, their grief becomes less intense and more manageable over time. Find someone who can allow you to mourn openly and freely and who will not label you as "weak" or "crazy".

## Confusing feelings...

You may experience a variety of feelings in your grieving process. *These may include but are not limited to:*

- ◆ **Shock, denial, numbness, disbelief:** These temporarily protect you from the full reality of the loss. They serve as a “psychological shock absorber” until you are more able to tolerate what you don’t want to believe.
- ◆ **Disorganization, confusion, searching, yearning:** Expect to forget things, to not be at your best. You may feel crazy, but you’re not. Other people may begin to look like the person you loved so much, because you want them to be there. Visual hallucinations such as this occur very frequently and are normal and expectable responses to grief. Dreams about the person are also very common.
- ◆ **Anxiety, panic, fear:** Your energy is drained, and you can easily feel overwhelmed by daily concerns. Take some time to relax or meditate every day.
- ◆ **Physiological changes:** You may experience trouble sleeping or low energy. You may need more rest than usual. Chronic existing health problems may become somewhat worse. Good self-care is important at this time; make sure you are getting enough to eat, and develop a regular eating and sleeping schedule. See your physician for a checkup.
- ◆ **Anger, rage, resentment, jealousy, blame, terror, explosive emotions:** Underneath them are usually feelings of pain, helplessness, and fear.
- ◆ **Guilt, remorse and regret:** You may feel guilt, remorse or regret about a variety of things: perhaps some things you did not say or do for your loved one; or, being angry with them before they departed. These are normal life events, and are usual parts of the imperfections of human relationships. Attempt to be more compassionate with yourself.

*Some other types of guilt related to death that some grieving people often experience can include but are not limited to:*

- ◆ **Survivor guilt** - the feeling that you should have died, instead of your loved one.
- ◆ **Relief guilt** – guilt about feeling relieved that your loved one died. Relief is natural and expectable, especially if a loved one suffered prior to death.
- ◆ **Joy guilt** – guilt about ever feeling happy again after a loved one has died. Joy is a natural and healthy experience in life. It is a sign that we are living life fully, which is something we must strive to return to following a significant loss.

## When Grief Lasts Too Long ...Or Is Too Intense:

Grief is typically viewed as a normal, though intense, form of sadness. However, grief can sometimes cause extreme or prolonged problems as the sadness evolves into serious disorders of anxiety and depression. If this occurs, it is an indication that counseling or therapy is needed. These extreme reactions may include:

- feelings of panic and/or frenzy
- feeling overwhelmed and incapacitated by fear and grief
- emotional numbness that does not go away
- going to extremes to avoid thinking about the loss, such as abusing drugs or alcohol, or becoming totally immersed in work
- intense symptoms of depression which may include: chronic insomnia which may be interrupted by early morning waking after falling asleep and difficulty falling back asleep; lack of appetite or overeating; lack of appetite for life such as relationships, sex, hobbies and recreation, or other things you used to find enjoyable; obsessive thoughts of death or thoughts of suicide.

## How can therapy help?

Often, people find that friends and family are not able to provide the level or kinds of support needed in the grieving or mourning process. Friends and family may be overwhelmed with their own grief, or be unable to provide support because they themselves have fallen victim to societal myths. A therapist can help you understand your grieving process by providing information and support. He or she can provide a place for you to grieve fully and naturally, and help you move through your grief to find continued meaning in life.

## Reference/Suggested Reading:

Wolfelt, Alan D. (1992). *Understanding Grief: Helping Yourself Heal*. Levittown, PA: Accelerated Development.

Go to the *Grief Recovery Institute* web site at:

<http://www.grief.net>

**Psychological  
Services  
Center**



## Your Counseling Service:

Timely, confidential, and professional assistance is available for U.C. students at the University *Psychological*

*Services Center* (8:00am – 5:00pm, M-F) located at 316 Dyer Hall. Phone (513-556-0648) or stop in for a no charge initial consultation interview.

This fact sheet is provided as a service by the University of Cincinnati Psychological Services Center and the Office of Student Affairs and Services. Contents of the fact sheet were prepared by Drs. Elizabeth Young, Jennifer Hartman, and Niki Rosenkranz and the professional staff of the Psychological Services Center. Please contact our office (513-556-0648) or our Web site at <http://www.psc.uc.edu> if you would like additional copies.

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## **WHAT TO EXPECT DURING YOUR BEREAVEMENT**

Whether you have experienced a loss before or not, the period of bereavement can be confusing, frightening, and exhausting. Processing your loss, adjusting to the changes in your life, and moving through your grief mean actively participating in the experience. Knowing what to expect or how to help yourself will help you navigate through the grief process.

- Grief may involve many different emotions, all of which are normal. For instance, you may feel sad, angry, guilty, afraid, or happy.
- You may feel confused or unable to focus. Feeling distracted is normal during the bereavement process.
- You may be angry at God and blame Him for the death.
- You may be angry at your loved one for leaving you. Then, you may feel guilty for being angry.
- You may have headaches, stomach aches, nausea, or feel anxious due to your grief.
- Your grief may seem different than your other family members' grief. You may each be reacting differently. Your grief will depend on your relationship with your loved one and how you perceive the loss. The same is true for everyone in your family.
- You and your family members may be at different points in the grief process. Don't expect everyone to be "at the same place" all the time. Grief in a family is like being on a roller coaster. The first car may be at the top of the hill, while the back car may be down in the valley. As the coaster moves, the first car goes down into the next valley, while the last car is now up on top of the hill. That is, you may be having a good day, while a family member is having a bad one. The next day, it may be reversed.
- Grief takes time and often lasts longer than most people think it will. Don't feel pressured to conform to others' beliefs of how long your grief should last. Allow yourself time to process and adjust to the changes in your life.
- Grief takes energy. You may feel tired or drained by the process.
- Your peers may not understand what you are going through. They may not know what to say to you or how to help. If possible, explain to trusted friends what would be helpful to you.
- You may feel a loss of identity due to the loss of your loved one. Your role in your family may feel like it is changing. Talk about these changes with someone you trust.

# HOW TO HELP YOURSELF DURING GRIEF

Grieving is an active process. You can do many things for yourself to help yourself grieve in a healthy, productive manner. While the bereavement process can be tiring and emotional, you can influence the experience by taking care of yourself and supporting yourself with people and activities that are helpful. Consider the following:

- Keep a regular schedule and get adequate sleep.
- Eat regular, healthy meals.
- Exercise regularly and moderately. Even taking a walk around the block can make you feel better.
  - Shoot hoops with a basketball, play tennis, roller blade, ice skate, or swim. Physical activity helps you “vent” your feelings.
- Talk to someone you trust. Many people find that talking helps you express and process your grief. Consider joining a grief support group for teenagers. Or talk with a trusted adult, such as an adult relative or family friend, your school counselor, a teacher, or clergy.
- Writing out your feelings and concerns can be very cathartic.
  - Keep a journal as one way of expressing your emotions.
  - Write a letter to your loved one to say things you may not have gotten the chance to say or to express how you feel now.
  - Write a letter to your grief and tell it how you feel.
  - Write poetry or a story, perhaps about your loved one or a favorite memory of him/her.
- Take a yoga class. Not only is this a physical activity, but it has a centering, grounding effect.
- Take a warm bubble bath.
- Read books on grief to help educate yourself and to connect to others who have had similar experiences. (see “Books For Teenagers” handout)
- Use appropriate websites to learn about grief and to share with other grieving teens. (see “Websites For Teenagers” handout)
- Wear or carry something special that reminds you of your loved one.
- Choose movies and TV shows carefully. For awhile, you may want to avoid those that are overly emotional or deal with death or loss.
- Allow yourself private time each day to remember your loved one or process some of the emotions that you are feeling.
- Let those around you know what helps you and what doesn’t.
- Accept support when it is offered.
- Pray and/or meditate.
- Spend time in nature. Hike in the woods, walk in a park, work in the yard, or plant in the garden.
- Prepare for special occasions or holidays. Be aware that these days may be especially difficult with the absence of your loved one.
- Participate in rituals or activities that honor your loved one. Light a candle, say a prayer, make a memory box, or create a scrapbook with favorite photographs and memories of your loved one.
- Give yourself time. Be gentle with yourself.

## WEBSITES FOR TEENAGERS

The following websites contain a variety of information on caregiving, grief, and mental health and wellness for teenagers, ages 13-18. Check out each site's links, as new sites and updated information continually become available. While none of these sites deal specifically with ALS, they all provide information that is applicable for teens who are helping care for a loved one with a chronic or life-threatening illness.

Also, please consider that as you care for a loved one with ALS, you may experience grief for a variety of losses, such as the loss of the "normal" life your family once experienced, the loss of your loved one's everyday involvement in your life, or the loss involved with changes in your friendships or ability to participate in your "regular" activities. The grief sites can help you deal with all of these losses as you experience them, including the anticipation and experience of your loved one's death.

[www.headroom.net.au](http://www.headroom.net.au)

The "HeadRoom" website was created by the South Australia Department of Health Services. "The Lounge" section contains mental health information written by young people for young people, ages 12 to 18. Under "Food for Thought," one can use the drop down menu to find information on a host of subjects, including loss & grief, depression, the ups & downs of family, and peer pressure. A solid source for information in a visually pleasing format.

[www.reachout.com.au](http://www.reachout.com.au)

"Reach Out!" is a web-based service that inspires young people (teens and college-age) to help themselves through tough times." "The issues" menu contains information on topics such as loss and grief, depression, and school issues. The "Family Issues" section also contains information specifically for young caregivers. By becoming a member of this website (which is free), one can access discussion forums, a personal journal, and bookmark capabilities, all designed with the young adult in mind. This Australian website includes the "Reach Out Central" interactive space, allowing members to participate on an "adventure" of one's own choosing to learn to deal with different age-appropriate situations.

[www.cyclopsact.org](http://www.cyclopsact.org)

Another Australian website, Cyclops is designed with tips and support for the young carer (under age 18), who is helping care for a sick loved one at home. Sections include getting help for yourself, tips in caring for yourself while you care for others, medical definitions, and "Time Out" with a guided relaxation exercise and links to other fun websites.

[www.youngcarers.net](http://www.youngcarers.net)

This British website was created specifically for young caregivers. Although some of the links are for regional support services, this site still offers interactive forums, posting sites, and support from other youth who are helping care for a sick loved one in their home.

<http://www.geocities.com/hotsprings/sauna/4424/index.html>

"Losing A Parent...A Resource for Young Adults Coping" is a website created by Kaz, a young man who has lost both his parents. His site includes his story, others' stories of parental loss, posted comments, memorials and poetry, and additional links. While it is

designed for young adults, the stories and information are pertinent to teens facing the loss of a parent or significant loved one.

[www.geocities.com/Athens/Forum/6811/yalp/](http://www.geocities.com/Athens/Forum/6811/yalp/)

“Young Adults Losing Parents” is another website designed by a young adult who shares the experience of losing a father and the subsequent lessons, feelings, and insights gained from that experience. Includes links, suggested books and music titles, and recommendations for coping.

[www.kidshealth.org/teen/](http://www.kidshealth.org/teen/)

This website is divided into sections for teens, parents, and kids. The teen section provides “doctor approved” information on a variety of health topics, including several resources on grief, depression, and anxiety. Click “Your Mind,” then “Death and Grief” for information specifically on bereavement.

<http://rd4u.org.uk/index.html>

“Road for You” is a website designed by young adults, ages 16-25. The site claims to be for ages 12-18, but will include posts from anyone up to age 25. It has numerous links to other resources as well as grief information, timeline and story posts, and places to share feelings. The “Fun Zone” offers games to just give yourself a break. A special “lads only” section is a chat room for young men.

[www.coolnurse.com](http://www.coolnurse.com)

Devoted to exploring a variety of health topics, this website is designed for teens and young adults. It offers grief information on “death of a parent” and “grieving friends” in the mental health section of the site map. These articles have links to similar articles. Additionally, this site offers a wealth of information on a variety of age-appropriate health and well-being topics.

[www.griefnet.org](http://www.griefnet.org)

This website’s focus is on-line support groups, divided by loss category. While not specifically for teenagers, the different groups could provide support from others going through similar loss. The “library” contains numerous articles and book suggestions on grief. The Kidsaid.com link addresses issues for younger children as well as teens.

Compiled by Beth S. Barrett, MSW  
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February, 2007

## **BOOKS FOR TEENAGERS**

The following books were written specifically for teenagers who have experienced the loss of a loved one. These books address issues of grief, the mixed emotions you may feel during your bereavement period, and ways to cope with these feelings and changes in your life. Remember that you have adults who love and care about you; share your questions, feelings, or concerns with them as you are ready. Remember, too, that your peers may not completely understand what you are going through. Sharing your experience with them or letting them read some of these books may offer them the opportunity to learn more about how they can support you through your grief. If you feel overwhelmed by or “stuck” in your grief, talk to a trusted adult, such as a parent, teacher, counselor, or clergy, who can help you.

***Fire in My Heart, Ice in My Veins: A Journal for Teenagers Experiencing a Loss***, by Enid Samuel Traisman. Publisher: Centering Corporation, 1992.

- This journal guides teenagers to use their creativity to process their grief. Activities include writing poems, lyrics, letters, and other activities addressing death and grief.

***Griefjourney: Notes of Grief for Teens, Young Adults and Anyone Who is Grieving*** by Mark Scrivani. Publisher: Centering Corporation, 2004.

- Discusses the emotions of grief and the pain of the holidays, saying goodbye, and coping. Includes information about how our love lives on and finding hope.

***Healing Your Grieving Heart for Teens*** by Alan D. Wohlfelt, Ph.D. Publisher: Companion Press, April, 2001.

- Written for teenagers, this book provides 100 practical ideas in helping understand, process, and move through the grief experience.

***Help for the Hard Times: Getting Through Loss*** by Earl Hipp. Publisher: Hazelden, 1995.

- Easy to read, this book provides straight talk about what loss and grief are and how to work through them. Included are grief facts, journaling suggestions, creative exercises, and ideas for caring for yourself during your grief journey.

***How It Feels When a Parent Dies***, by Jill Kremetz. Publisher: Peter Smith Publisher, 1993.

- Eighteen children, ages 7-17, discuss death, grief, and their experiences of loss from a loved one dying.

***I Will Remember You: What to do when someone you love dies; A Guidebook Through Grief for Teens*** by Laura Dower. Publisher: Scholastic, Inc., April, 2001.

- This book is written for teens, offering valuable insight, information, and activities. Each chapter addresses a different aspect of grief, offering “try this” exercises, personal stories, and practical suggestions for taking care of yourself as you move through grief.

***Straight Talk about Death for Teenagers: How to Cope with Losing Someone You Love***, by Earl A. Grollman. Publisher: Beacon Press, 1993.

- This book provides stories, advice, and guidance written with teenagers in mind. The author discusses different aspects of grief and utilizes a workbook component to assist in helping you understand and process your grief.

***The Grieving Teen: A Guide for Teenagers and Their Friends***, by Helen Fitzgerald. Publisher: Fireside, 2000.

- The author addresses typical questions that young people have about death. Each chapter has a follow-up section called "What You Can Do." This comprehensive book covers a multitude of topics on death and grief.

***The Next Place*** by Warren Hanson. Publisher: Waldman House Press, 1997.

- This beautiful picture book describes a journey to a place where earthly hurts are left behind. The colorful illustrations and rhythmic poem will comfort the child in all of us.

***You Can Get There From Here: Journaling Through the Grief, a Guide for Teens and Young Adults*** by Leah Hawley. Publisher: Keuka-Saguaro Publishing, July, 2005.

- This book contains a program of journaling with a year's worth of thoughts, activities, and information in a format designed specifically for the teenager's interests and understandings.

For additional books on grief, look in the psychological section of the book store or type in "grief" for a search on [www.amazon.com](http://www.amazon.com). Many new and used books can be purchased on Amazon at a reduced price.

Also, two catalogue companies specialize in books and other print resources on grief. Their websites are: [www.compassionbooks.com](http://www.compassionbooks.com) and [www.centering.com](http://www.centering.com).

## Gone From My Sight

I am standing upon the seashore.  
A ship at my side spreads her white  
sails to the morning breeze and starts  
for the blue ocean.

She is an object of beauty and strength.  
I stand and watch her until at length  
she hangs like a speck of white cloud  
just where the sea and sky come  
to mingle with each other

Then someone at my side says;  
"There, she is gone!"

"Gone where?"  
Gone from my sight. That is all.  
She is just as large in mast and hull  
and spar as she was when she left my side  
and she is just as able to bear her  
load of living freight to her destined port.  
Her diminished size is in me, not in her.

And just at the moment when someone  
at my side says, "There, she is gone!"  
There are other eyes watching her coming,  
and other voices ready to take up the glad  
shout,  
"Here she comes!"

And that is dying.

~Henry Van Dyke

# YOUNG ADULTS

(ages 18-25):

Information  
to help you through  
your grieving process

*“Give yourself time to grieve.  
It may take several years just to accept the finality of a loss,  
that someone is gone forever,  
and even more to work through your emotions.”*

*~Karen Katafiasz*

# GRIEF

## What Is Grief?

Grief is a natural emotional reaction to a significant loss or expected loss. It is an essential component of the eventual emotional process of recovery from loss. Grief usually occurs in response to many different types of loss, including:

- the death of a loved one
- the end or breakup of a significant relationship
- a loved one experiencing a chronic or terminal illness
- the loss of an important life factor, such as financial security or a job you like
- the death of a pet
- a significant negative change in health or physical functioning

## Grief vs. Mourning

**Grief** is the internal experience of loss; the thoughts and feelings about a loss that you experience within yourself.

**Mourning** is the outward expression of grief. Crying, talking about the person who died, or celebrating memories and anniversary dates are all ways of mourning.

*At times, we must grieve alone, but mourning is also necessary so that you are not alone.*

## When helping people who grieve, it is important that you do **NOT**...

- Withdraw from the survivor, removing your support.
- Suggest positive outcomes from the loss.
- Mention that the death could have been prevented in some way (e.g., If only....).
- Rationalize positive aspects the death.
- Compare the survivor's grief reaction to other people you know.
- Dwell on your own grief to show your sorrow.
- Become frightened by intense emotions and then retreat from the situation.
- Try to talk them out of their feelings.
- Force physical gestures (*i.e., hug, holding hands, etc.*). If unsure, it can be helpful to extend a hand to touch them and if they appear uncomfortable it is best to retreat and offer silent support without touch.
- Take rejection by the survivor as a personal attack on you or your relationship with the survivor.

## Myths about the grief process

**Myth:** *The experience of grief and mourning proceed in predictable and orderly stages, such as denial, anger, guilt etc.*

This stages-of-grief idea is appealing, but inaccurate. It emerged from Elisabeth Kubler-Ross' groundbreaking book, *On Death and Dying*. However, Dr. Kubler-Ross did not intend for these emotions to be interpreted as stages or steps, but rather to help people understand that denial, anger, guilt, and sadness are common, normal and expected reactions. If

you are experiencing anger, it doesn't mean that you are "less evolved" than someone feeling guilt. Many people do not fully experience all of these feelings. Who is to say what is a "normal" feeling for every person when you have lost someone you loved? Find people who accept you and your grief, and who allow you to be where you happen to be in the grieving process.

## "Be Strong"

**Myth:** *After losing someone you love, your goal should be to "be strong", and "get over" your grief as soon as possible. Crying means that you are "falling apart", and that is not what anyone wants.*

Crying is nature's way of releasing tension, and it lets others know that you need to be comforted. When stress is high, crying even discharges accumulating stress toxins within our tears.

Society often encourages people to quickly move away from grief. Unfortunately, refusing to cry, suffering in silence, and "being strong" are often viewed as admirable and desirable reactions to loss. Friends, family, and co-workers may encourage this stance because they don't want to talk about painful things, and there is nothing they can say or do to make it better. Many people have internalized the idea that grieving and mourning should be done quickly, quietly, and efficiently. The message from others seems to be, "Just get over it."

Find someone who accepts that no one can "make it better", and that your life surely will not be the same without the person (or pet) you loved. Find someone who can be present with you while you grieve so you do not have to bear it all alone. In time, you can learn to live with your grief while you learn to adjust to life without the presence of person (pet) who has departed.

## "How long should grief last?"

**Myth:** *It takes between three months and a year to "get over" losing someone you love.*

This question relates directly to our culture's impatience with bereavement and the desire to move people away from the process of mourning as quickly as possible. We expect grieving people to "get back to normal" soon after the death or loss. All too often, we succumb to the myth that grief should be moved away from rather than moved toward, as something to be *overcome*, rather than experienced. Interestingly, when people are allowed to move toward their grief and to mourn openly, their grief becomes less intense and more manageable over time. Find someone who can allow you to mourn openly and freely and who will not label you as "weak" or "crazy".

## Confusing feelings...

You may experience a variety of feelings in your grieving process. *These may include but are not limited to:*

- ◆ **Shock, denial, numbness, disbelief:** These temporarily protect you from the full reality of the loss. They serve as a “psychological shock absorber” until you are more able to tolerate what you don’t want to believe.
- ◆ **Disorganization, confusion, searching, yearning:** Expect to forget things, to not be at your best. You may feel crazy, but you’re not. Other people may begin to look like the person you loved so much, because you want them to be there. Visual hallucinations such as this occur very frequently and are normal and expectable responses to grief. Dreams about the person are also very common.
- ◆ **Anxiety, panic, fear:** Your energy is drained, and you can easily feel overwhelmed by daily concerns. Take some time to relax or meditate every day.
- ◆ **Physiological changes:** You may experience trouble sleeping or low energy. You may need more rest than usual. Chronic existing health problems may become somewhat worse. Good self-care is important at this time; make sure you are getting enough to eat, and develop a regular eating and sleeping schedule. See your physician for a checkup.
- ◆ **Anger, rage, resentment, jealousy, blame, terror, explosive emotions:** Underneath them are usually feelings of pain, helplessness, and fear.
- ◆ **Guilt, remorse and regret:** You may feel guilt, remorse or regret about a variety of things: perhaps some things you did not say or do for your loved one; or, being angry with them before they departed. These are normal life events, and are usual parts of the imperfections of human relationships. Attempt to be more compassionate with yourself.

*Some other types of guilt related to death that some grieving people often experience can include but are not limited to:*

- ◆ **Survivor guilt** - the feeling that you should have died, instead of your loved one.
- ◆ **Relief guilt** – guilt about feeling relieved that your loved one died. Relief is natural and expectable, especially if a loved one suffered prior to death.
- ◆ **Joy guilt** – guilt about ever feeling happy again after a loved one has died. Joy is a natural and healthy experience in life. It is a sign that we are living life fully, which is something we must strive to return to following a significant loss.

## When Grief Lasts Too Long ...Or Is Too Intense:

Grief is typically viewed as a normal, though intense, form of sadness. However, grief can sometimes cause extreme or prolonged problems as the sadness evolves into serious disorders of anxiety and depression. If this occurs, it is an indication that counseling or therapy is needed. These extreme reactions may include:

- feelings of panic and/or frenzy
- feeling overwhelmed and incapacitated by fear and grief
- emotional numbness that does not go away
- going to extremes to avoid thinking about the loss, such as abusing drugs or alcohol, or becoming totally immersed in work
- intense symptoms of depression which may include: chronic insomnia which may be interrupted by early morning waking after falling asleep and difficulty falling back asleep; lack of appetite or overeating; lack of appetite for life such as relationships, sex, hobbies and recreation, or other things you used to find enjoyable; obsessive thoughts of death or thoughts of suicide.

## How can therapy help?

Often, people find that friends and family are not able to provide the level or kinds of support needed in the grieving or mourning process. Friends and family may be overwhelmed with their own grief, or be unable to provide support because they themselves have fallen victim to societal myths. A therapist can help you understand your grieving process by providing information and support. He or she can provide a place for you to grieve fully and naturally, and help you move through your grief to find continued meaning in life.

## Reference/Suggested Reading:

Wolfelt, Alan D. (1992). *Understanding Grief: Helping Yourself Heal*. Levittown, PA: Accelerated Development.

Go to the *Grief Recovery Institute* web site at:

<http://www.grief.net>

**Psychological  
Services  
Center**



## Your Counseling Service:

Timely, confidential, and professional assistance is available for U.C. students at the University *Psychological*

*Services Center* (8:00am – 5:00pm, M-F) located at 316 Dyer Hall. Phone (513-556-0648) or stop in for a no charge initial consultation interview.

This fact sheet is provided as a service by the University of Cincinnati Psychological Services Center and the Office of Student Affairs and Services. Contents of the fact sheet were prepared by Drs. Elizabeth Young, Jennifer Hartman, and Niki Rosenkranz and the professional staff of the Psychological Services Center. Please contact our office (513-556-0648) or our Web site at <http://www.psc.uc.edu> if you would like additional copies.

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# Living With Loss

## Understanding the Personal Response to Grief

In the course of our lifetime, each of us develops relationships with others which take on special meaning to us. They may be parents, other family members, friends, teachers, even our pets. These are the people who in a variety of ways through nurturing and challenging us help us become who we are. Over the course of our life, each of us also experiences the death of someone we love. Whether this loss occurs as a result of illness, accident, or other trauma, we are left with a mixture of thoughts and feelings. We deeply sense their absence. The following suggestions are offered to assist us in understanding the constructive process of grief and the importance of remembering our loved one.

### It is important to accept yourself

Grief is a natural and universal experience. Each of us, however, experiences loss in ways which are characteristic to our upbringing and personalities. While common elements exist in the bereavement process, there are no fixed formulas or schedules to which we must conform. Accepting yourself is an important step toward a healthy grief process.

### Your feelings are normal

Following the loss of a loved one, a range of emotions may be experienced. These feelings include sadness, fear, despair, confusion, anger, guilt, and even a sense of numbness. These emotions may be felt in varying degrees of intensity and over differing periods of time. Our daily living patterns may trigger memories of our loss and associated feelings. Family celebrations, holidays, favorite places, songs, and experiences which were formerly shared with the loved one may remind us of our suffering. In the midst of our grieving, it is normal for us to wonder if our sorrow will ever subside. In time the memories of our loved one will remain, but the intensity of our strongest emotions is moderated. Even so, it is important to remember that over the years we do not forget the person. It may be helpful to think of your bereavement as a cycle in which periodically you are reminded of the loss and associated feelings.

### Your daily routine may change

Following the death of a significant other, a person may feel quite different. You may be physically fatigued, have difficulty with your usual sleep pattern, experience an inability to concentrate for long periods, and lose some of your normal appetite. You may also find that your interest in work, social activities, and being with others diminishes somewhat. Activities and people you usually enjoy may seem to hold less attraction. During this period, some persons increase their involvement in work related and social activities in order to preoccupy their mind and energy and avoid some of the uncomfortable feelings associated with loss.

However a person chooses to adapt, it is important to value and maintain connections with others and engage in a healthy balance through work, leisure, and rest. Plan to participate in some form of relaxation and a physical activity like walking, perhaps in the company of another person. If significant changes which affect your ability to function on a daily basis persist, this may be a cue to see a professional for consultation and specialized assistance.

# Constructing a Hopeful Future

## Be kind to yourself

Try to establish reasonable expectations about your ability and energy to meet current responsibilities. Guard against taking on new projects too soon. Remember that bereavement with its differing levels of intensity is a natural and essential process for remembering the loved one.

## Create ways of remembering your loved one

Rituals can help us recall the positive dimensions of our relationship and connect us with community. Activities like journal writing, meditation, prayer, walking, singing, and visiting places formerly shared with the loved one can be creative outlets for your thoughts and feelings. They may also help remind us of the value of life itself.

## Center yourself spiritually

Remind yourself of goals you have set for yourself. Remember the ways your loved one contributed to helping you develop and achieve your potentials. Imagine a future purpose for yourself and ways you wish to contribute to others. Seek to remind yourself in a variety of ways that your life has meaning. If you practice a religion, utilize its symbols, activities, and community to comfort and provide perspective.

## Envision a hopeful future

Share your thoughts and feelings with others. Allow them to be with you during this very important part of life. Try to remain physically active and sensitive to the beauty of life around you. Imagine there can be meaning to your future. Envision the love you felt for the person you lost will survive as a foundation for a creative future.

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[www.counsel.ufl.edu/brochure.asp?include=brochures/living\\_with\\_loss.brochure](http://www.counsel.ufl.edu/brochure.asp?include=brochures/living_with_loss.brochure) on  
[April 2, 2007](#).

# Self-Help: Handling Grief

Grief occurs in response to the loss of someone or something. The loss may involve:

- End of a relationship
- A move to a new community
- The death of a friend, family, important person or pet
- Life-threatening illness of a loved one.
- Sudden closing of a much anticipated opportunity or life goal

Grieving such losses is important because it allows us to 'free-up' energy bound to the lost person or experience, so that we might re-invest that energy elsewhere. Until we grieve effectively, we are likely to find reinvesting difficult; a part of us remains tied to the past.

Grief, itself, is a normal and natural response to loss. There are a variety of ways that individuals respond to loss. Some are healthy, coping mechanisms, and some may hinder the grieving process. Grieving is not forgetting, nor is it drowning in tears. Healthy grieving results in an ability to remember the importance of our loss -- but with a new-found sense of peace, rather than searing pain. It is important to realize that acknowledging the grief promotes the healing process. Time and support facilitate the grieving process, allowing an opportunity to appropriately mourn the loss.

## Common Reactions to Loss:

Individuals experiencing grief from a loss may choose a variety of ways of expressing it. It is important to note that common phases of grief exist; however, they do not depict a specific way to respond to loss. Rather, stages of grief reflect a variety of reactions that may surface as an individual makes sense of how this loss affects them. Stages may occur in a different order for many people.

**Denial, numbness, and shock** This protects the individual from experiencing the intensity of the loss. Numbness is a normal reaction to an immediate loss and should not be confused with "lack of caring". Denial and disbelief will diminish as the individual slowly acknowledges the impact of this loss and accompanying feelings.

**Bargaining** At times, individuals may ruminate about what could have been done to prevent the loss or to change the negative outcomes. You may bargain (or promise) with yourself or with God in order to change the loss or its consequences. This reaction can provide insight into the impact of the loss; however, if not properly resolved, intense feelings of remorse or guilt may hinder the healing process. Individuals can become preoccupied about ways that things could have been better, imagining all the things that will never be.

**Depression** After recognizing the true extent of the loss, some individuals may experience depressive symptoms. Sleep and appetite disturbance, lack of energy and concentration, and crying spells are some typical symptoms. Feelings of loneliness, emptiness, isolation, and self-pity can also surface during this phase, contributing to this reactive depression. For many, this phase must be experienced in order to begin reorganizing one's life.

**Anger** This reaction usually occurs when an individual feels helpless and powerless. Anger may result from feeling abandoned, occurring in cases of loss through death. Feelings of resentment may occur toward oneself, a higher power or toward life in general for the injustice of this loss. After an individual acknowledges anger, guilt may surface due to these negative feelings. Again, these feelings are natural and should be honored to resolve the grief.

**Acceptance** Time gives the individual an opportunity to resolve a range of feelings that surface. The grieving process supports the individual. That is, healing occurs when the loss integrates into the individual's set of life experiences. Individuals may return to some of the earlier feelings in life. There is no time limit to the grieving process. Each individual should define one's own healing process.

### **Guidelines that may help resolve grief**

- Good friends, family members, or a personal counselor can help to do this vital work. You can also do a good deal to help yourself.
- Allow time to experience your thoughts and feelings openly to yourself.
- Acknowledge and accept all feelings, both positive and negative.
- Use a journal to document the healing process.
- Confide in a friend; tell the story of the loss.
- Crying offers a release.
- Identify unfinished business. Work towards resolution.
- Bereavement groups provide opportunities to share with others who have experienced loss.
- Go gently -- take time it needs, don't give yourself a deadline for being "over it";
- Expect and accept some reduction in your usual efficiency and consistency;
- Try to avoid taking on new responsibilities or making major life decisions for a time;
- There are many helpful books on grief. If grief is understood it is easier to handle;
- Allow yourself to enjoy without guilt, some GOOD TIMES.
- Tell those around you what helps you and what doesn't. Most people would like to help if they knew how;
- Plan for special days such as holidays /anniversaries. Feelings can be intense at these times;
- Pray, meditate or take quiet time:
- Connect on the Internet. There are many resources for people in grief, as well as opportunities to chat with fellow grievers;
- Speak to a member of the clergy;
- Do something to help someone else.

If the healing process becomes too overwhelming, seek professional help.

### **Factors that hinder the healing process:**

- Avoidance or minimization of one's emotions.
- Use of alcohol or drugs to self-medicate.
- Use of work, schoolwork, constant socializing to avoid feelings

## **How Do You Do Grief Work?**

Fortunately, much of the process of healthy grieving seems to be 'built into' our genes. Acknowledging and growing from losses is such a natural process that much of it will happen without our direction -- if we relax our expectations of how we "should" grieve and give up some of our need to be in control.

But healthy grieving is an active process; it is NOT true that, "You just need to give it time." One way of understanding the work to be done is to think of grieving as a series of tasks we need to complete (not necessarily in sequence):

- To acknowledge and express the full range of feelings we experience as a result of the loss;
- To 'say good-bye,' and to move to a new peace with the loss.
- To accept the finality of the loss;
- To adjust to a life in which the lost person, object, or experience is absent

Excerpted from The University of Texas at Dallas website at [www.utdallas.edu/counseling/selfhelp/handling-grief.html](http://www.utdallas.edu/counseling/selfhelp/handling-grief.html) on April 2, 2007.

# Coping with Grief

People who have been affected by a death or other loss are likely to experience feelings of grief. Grief is a normal, appropriate emotional response to loss. As people grieve they may experience a variety of emotions including shock, sadness, depression, anxiety, hostility, guilt, fear, and, with time, acceptance. They may also move back and forth between good memories and bad memories. While the grieving process is difficult, there are things that can help people heal more quickly and integrate the loss into their lives in a positive way. Talking with trusted friends and family members about your memories, feelings, and thoughts will be helpful. Keeping a daily routine will help you create a sense of stability as you reorganize your life and your worldview. It is also important to set aside time to do things that make you feel good. Eating regular meals, getting adequate sleep, and exercising can also be helpful. If your feelings of grief and loss are interfering with your ability to function in your daily life, you may want to consider receiving counseling.

## Surviving Loss: 10 Suggestions

The loss of a loved one through death often requires adjustment in our way of looking at the world and our plans for living in it. It is a major disruption in our lives, and people's reactions differ. A positive self-image, an ability to relate easily, a faith to lean on and a willingness to take initiative are ways of being and interacting that can help people manage feelings of grief.

Grief therapist C.M. Parker suggests that the pain of grief is the price we have to pay for love. In a very real way, whenever we choose to love someone, we are also choosing to be hurt. The time comes when we have to say good-bye and let go. That is when our grief begins. As it takes time to love, so it also takes time to let go. People say, "Time heals." Yet time by itself doesn't heal. If a person in grief sits in a corner waiting for time to take care of bitter sorrow, time won't do anything. It is what we do with time that can heal.

Bereaved people may find themselves feeling stranded in their own grief. To counteract this, the following suggestions are offered as guidelines about how the bereaved can use their time to find their way to hope, freedom and healing.

**1. Take Time To Accept Death.** Facing and accepting death remains a necessary condition for continuing our own life. Often it is hard to realize that what happened has really happened and that life has changed. We hope that it was all a bad dream. We hope that our loved one will call us from work or that we are going to hear that person's voice when we step into the house. The only way to deal with death, no matter how painful that might be, is to accept it, not fight it. Yes, our loved one has died. But that doesn't mean that we have to die, too. We have to pick up the pieces and go on from there.

**2. Take Time To Let Go.** One of the most difficult human experiences is letting go. Yet from birth to death life is a series of letting go - sometimes temporarily, sometimes permanently. Letting go reminds us that we are not in control of life, and that we need to accept what we cannot control. Letting go means adjusting to a new reality in which our loved one is no longer present. And yet, many bereaved continue to believe that their loved one has not really died, that life hasn't really changed. Letting go takes place when the "we" becomes "I," when we are able to substitute the memories of the

deceased for their physical presence and when we are able to change patterns in our lives and in our environment. Letting go occurs when we are able to endure and accept the feelings that accompany death.

**3. Take Time To Make Decisions.** People who have been very dependent on the deceased find themselves lost in the world. They are afraid to give themselves direction, to make mistakes, to ask, to try. Yet making mistakes is the way in which we learn and develop trust in ourselves. We need to be patient with ourselves as we gradually learn to make decisions.

**4. Take Time To Share.** The greatest need of the bereaved is to have someone to share their pain, their memories and their sadness. In life, we can only accept that which we can share. Bereaved people need others to give them time and space to grieve. When you are grieving, you might need someone who looks backward, because the past, not the future, remains the source of comfort in the early stages of grief. Sharing our memories and feelings with people who are grieving themselves is especially helpful and therapeutic.

**5. Take Time To Believe.** To survive is to find meaning in suffering. Suffering that has meaning to it is endurable. However, meaning doesn't just happen. At times, our grief can shake up our faith. For many people, religion-- with its rituals, the promise of an afterlife and its community support--offers a comforting and strengthening base in the lonely encounter with helplessness and hopelessness. Our faith does not take away our grief but helps us live with it.

**6. Take Time To Forgive.** The feeling of guilt and the need for forgiveness accompany many of our experiences, especially those that have remained unfinished. We might feel guilty about what we did or didn't do, about the clues we missed, about the things we said or failed to say. As we review our lives and our relationship with the deceased, there will always be things which are less than ideal. We need to accept our imperfections and make peace with ourselves.

We cannot judge our yesterdays with the knowledge of today. So torturing ourselves for the things we did and wished we hadn't done, or dwelling on the things we didn't do, doesn't change anything. It only makes us miserable. We certainly need to own and express our anger, but there is also a need for forgiveness.

**7. Take Time To Feel Good.** Bereaved people are not sentenced to unhappiness. We are not born happy or unhappy. We learn to be happy by the way we adjust to life-crises and use the opportunities life gives us. We need to be patient and give ourselves time to learn and time to make mistakes. We especially need to affirm ourselves and pat ourselves on the back for every small thing we learn to do, for this is when we "expand" ourselves. The death of a loved one affects our life-style and changes our self-image. Grief can rapidly shape us and help us discover a new independence and outlook on things.

**8. Take Time To Make New Friends.** Loneliness will be present in grief, and it might be nature's way of mending our broken hearts. Loneliness can also be transformed into solitude. That happens when we are not oppressed by our loneliness, but learn to live creatively with it by cultivating our inner resources and self-understanding. In the grief process, healing occurs when we take the step to move out of our safe boundaries and interact with others. Old friends might be there to offer security and comfort; new

friends will be there to offer opportunities. We might meet these new people through a support group, a card club, or at a class. We need friends on the road to recovery.

**9. Take Time To Laugh.** In life there are as many reasons to laugh as there are to cry. In grief there is a time when our tears come with less frequency and intensity, and we learn to remember without crying. Laughter, on the other hand, helps us survive, and it helps us reenter life. Laughter helps us accept our limitations and develops hope in the present. Laughter defines our movement from helplessness to hopefulness.

**10. Take Time To Give.** A way to overcome our loneliness and pain is to be concerned about the loneliness and pain of others. People turn away from grief when they feel wanted and needed by the living. Being able to help someone gives us meaning. So if we find someone else who needs us it can be an opportunity for our own healing. Getting involved with others gives us the feeling that life goes on and takes us away from self-pity. Listening to someone, empathizing and sharing over the telephone, providing information or going out to lunch together are ways to give of yourself.

There is a tremendous wisdom that is accumulated in one's encounter with grief, and it needs to be shared. Healing takes place when we turn our pain into a positive experience, and we realize that helping others is the key to helping ourselves. The road to recovery from grief, therefore, is to take time to do things which will enable us to give a renewed meaning to our lives. In grief, no one can take away our pain because no one can take away our love. The call of life is to learn to love...again.

Excerpted from the Western Washington University website at [www.wvu.edu/chw/counseling/subpages/subselfhelp/grief.shtml](http://www.wvu.edu/chw/counseling/subpages/subselfhelp/grief.shtml) on April 2, 2007.

## **Realistic Expectations for Yourself During Grief**

The grief process can be a slow, emotional, and confusing period. The following are realistic expectations for yourself as you journey through your grief. Remember to not be too hard on yourself. All of these situations can be normal occurrences during grief.

- Your grief will take longer than you and most people think it will.
- Your grief will take lots of energy, sometimes leaving you feeling tired or exhausted.
- Your grief will show itself in all elements of your life: emotional, physical, mental, and spiritual.
- Your grief will involve many changes and will continue to develop.
- Your grief will depend on how you perceive the loss and on your relationship with the deceased.
- You will grieve for many things both symbolic and concrete, not just the death itself.
  - You will grieve for what you have already lost and for what you have lost for the future.
  - Your grief will include mourning for lost hopes, dreams, and unfulfilled expectations you held for and with the person you lost.
- Your grief will involve a wide variety of feelings, ideas, and reactions, not just feelings of sadness or depression.
- Your loss may resurrect old issues, feelings or unresolved conflicts from the past.
- You may feel a loss of identity due to your loss.
- You may experience feelings that are unfamiliar to you.
- You may feel emotions toward your loved one that confuse you or make you feel guilty for feeling them:
  - You may feel anger toward your loved one or blame them for leaving you.
  - You may feel guilty for something you said or did, or did not say or do, to your loved one before they died.
- You may feel anger toward or blame the medical profession or other people for your loved one's death.
- You may blame God for your loved one's death.
- You may have trouble thinking or concentrating.
- You may feel obsessed with the death or preoccupied with the deceased.
- You may question your religion or begin searching for meaning in your loss.
- You act differently socially.
- You may have physical reactions to your grief, such as headaches, stomach aches, anxiety attacks, nausea, etc.
- Society will have unrealistic expectations about your mourning and may respond inappropriately to you.
- You may find certain dates will affect you emotionally, such as the deceased's birthday or the anniversary of the death.
- You may find that future milestones in your life, such as graduation from college or getting married, will be coupled with grief temporarily.

## Helping Yourself Through Grief

Active, healthy grieving requires balance -- balancing the time you spend directly working on your grief with the time you spend coping with your day-to-day life; balancing the amount of time you spend with others with the time you spend alone; balancing your need for help from others with caring for yourself. Focusing too strongly on any single side of these pairings is getting off-track.

Here are some things others have found useful in their healthy grieving. Choose the ones that fit for you, or make up your own methods of self-care. Remember that grieving is an active process, it takes energy that will likely have to be temporarily withdrawn from the usual pursuits of your life. Treat yourself with the same care, tolerance, and affection you would extend to a valued friend in a similar situation.

- Go gently -- take whatever time it needs, rather than giving yourself a deadline for when you should be "over it"
- Expect and accept some reduction in your usual efficiency and consistency
- Try to avoid taking on new responsibilities or making major life decisions for a time
- Talk regularly about your grief and your memories with someone you trust
- Accept help and support when offered
- Be particularly attentive to maintaining healthy eating and sleeping patterns
- Exercise moderately and regularly
- Keep a journal
- Read -- there are many helpful books on grief; some are listed below. If grief is understood it is easier to handle
- Plan, and allow yourself to enjoy without guilt, some GOOD TIMES. The goal is balance, not martyrdom
- Carry or wear a linking object -- a keepsake that symbolically reminds you of your loss. Anticipate the time in the future when you no longer need to carry this reminder and gently let it go
- Tell those around you what helps you and what doesn't. Most people would like to help if they knew how
- Take warm, leisurely baths
- See a grief counselor
- Get a massage regularly
- Set aside a specific private time daily to remember and experience whatever feelings arise with the memories
- Choose your entertainment carefully -- some movies, TV shows, or books can only over-intensify already strong feelings
- Join a support group -- there are hundreds of such groups and people have a wonderful capacity to help each other
- Plan for 'special days' such as holidays or anniversaries. Feelings can be particularly intense at these times

- Pray
- Take a yoga class
- Connect on the Internet. There are many resources for people in grief, as well as opportunities to chat with fellow grievers
- Vent your anger in healthy ways, rather than holding it in. A brisk walk or a game of tennis can help
- Speak to a member of the clergy
- Plant yourself in nature
- Do something to help someone else
- Write down your lessons. Healthy grieving will have much to teach you.

Excerpted from The University of Montana, MontanaTech website at [www.mtech.edu/student\\_life/counseling/grieving.htm](http://www.mtech.edu/student_life/counseling/grieving.htm) on April 2, 2007.

# GriefNet Library: Young Adults and Grief

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## Silence is Not an Answer in the Time of Grief

by Elizabeth Cross McDonald

This summer I survived the two most devastating realities I have experienced since my father's death in 1980. The first was anguishing in its inevitability: my 31 year old brother's death from the cancer that stalked him for seven years. The second was worsened by its utter uselessness and avoidability: the deliberate way virtually every friend and acquaintance, save my very closest, has avoided and ignored me during this time of grief.

I do not believe that those who knew about Al's death did not worry about me and my family. It is likely that many were concerned. But I know that most of my friends are young, and have not yet had a close family member die. Death is scary or unreal, and few can envision themselves in the position I have been in twice. In a word, they are ignorant about my feelings and how to react to them.

A few of the braver approached me with hearty, superficial greetings that suggested my absence but not its cause: "Well hello, nice to see you back" or "So school's about to start, are you ready?" This was, for all its well meaning, very painful for me. I felt these people were using trivialities as a way of saying, "These things are more important than his death, and I'm more concerned about today's weather than how terrible you feel." With uneasy smiles on their faces, these people made me feel like a fool.

To a few, I said, "Perhaps you didn't know my brother died." The response was a muffled, "Oh, yes... I'm sorry." I stopped volunteering this information: it was awful to realize that these people, through all the banality, knew about Albert, and said nothing. Some people undoubtedly kept silent in the hopes that I would approach them to talk and they could then be duly supportive. This was a gross error of judgment. I needed to have friends voluntarily open their hearts in sympathy, as I was feeling vulnerable and afraid that those I turned to might turn me away. To me, the silence said, "Leave me alone, I don't care."

Still others made efforts to engage me in conversation, as long as I was able to be cheerful and not talk about Albert. To these people, my casual comment like, "Oh, I remember when Albert and I visited that person" was nervously ignored and met by an embarrassed silence. I needed to be able to remember my brother reflectively, without self-consciousness or shame. And even close friends could not understand that waves of grief, anger and depression affected me in ways I myself could not understand. How I needed their patience and support, their faith that I was angry at Death, and not at them.

My grief is now settling into the long depression that is a necessary step to healing. But every week, people on campus - maybe your friend or roommate - also face the unthinkable tragedy in a place where youth can lead people to feel immortal. These people need your

support, and it's not hard to give it to them. If someone you know, whether closely or just vaguely, is bereaved, please don't be shy or afraid. Take the initiative, walk up, look into his or her eyes and say, "I am so sorry to hear about the death." (Only one person did this to me. Though I was not particularly close to him, his generosity moved me to tears.)

You need not give your philosophy on tragedy in life or your favorite remedy for depression. The bereaved person does not expect or want this. And if you consider yourself to be a close friend of the bereaved person, now is your chance to prove it. Listening - not avoiding the bereaved's sadness or being afraid to have the friend cry to you - is essential. If your friend does cry, consider yourself lucky that he or she is comfortable enough to share these deep emotions with you.

And don't try to stop the tears - they are also a step to healing and must flow freely. If you feel anger or hostility directed at you, take comfort that anger and grief are interconnected. The friend is not angry at you, it is simply his desperate attempt to justify or focus the waves of anger and desolation that surge uncontrollably through him. If the bereaved are surrounded by people who care, the grieving process is made less bitter and devastating. Yet caring and concern for your friend is meaningless unless you directly tell her that you do care.

I understand that Dad and Albert had no intention of abandoning me, that they left me through no power of their own. The intentions of my silent friends are much less clear. Remember this: Just say, "I heard, and I'm sorry."

- Chicago, 1987

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Grace happens

## WEBSITES FOR YOUNG ADULTS

The following websites contain a variety of information on caregiving, grief, and mental health and wellness for the young adult. These sites are appropriate for teens, college-age students and young adults (ages 18-25). Check out each site's links, as new sites and updated information continually become available. While none of these sites deal specifically with ALS, they all provide information that is applicable to young adults and teens who are helping care for a loved one with a chronic or life-threatening illness.

Also, please consider that as you care for a loved one with ALS, you may experience grief for a variety of losses, such as the loss of the "normal" life your family once experienced, the loss of your loved one's everyday involvement in your life, or the loss involved with changes in your friendships or ability to participate in your "regular" activities. The grief sites can help you deal with all of these losses as you experience them, including the anticipation and experience of your loved one's death.

### [www.headroom.net.au](http://www.headroom.net.au)

The "HeadRoom" website was created by the South Australia Department of Health Services. "The Lounge" section contains mental health information written by young people for young people, ages 12 to 18. Under "Food for Thought," one can use the drop down menu to find information on a host of subjects, including loss & grief, depression, the ups & downs of family, and peer pressure. A solid source for information in a visually pleasing format.

### [www.reachout.com.au](http://www.reachout.com.au)

"Reach Out! is a web-based service that inspires young people to help themselves through tough times." "The issues" menu contains information on topics such as loss and grief, depression, and school issues. The "Family Issues" section also contains information specifically for young caregivers. By becoming a member of this website (which is free), one can access discussion forums, a personal journal, and bookmark capabilities, all designed with the young adult in mind. This Australian website includes the "Reach Out Central" interactive space, allowing members to participate on an "adventure" of one's own choosing to learn to deal with different age-appropriate situations.

### [www.cyclopsact.org](http://www.cyclopsact.org)

Another Australian website, Cyclops is designed with tips and support for the young carer, who is helping care for a sick loved one at home. Sections include getting help for yourself, tips in caring for yourself while you care for others, medical definitions, and "Time Out" with a guided relaxation exercise and links to other fun websites.

### [www.youngcarers.net](http://www.youngcarers.net)

This British website was created specifically for young caregivers. Although some of the links are to regional support services, this site still offers interactive forums, posting sites, and support from other youth who are helping care for a sick loved one in their home. The "Moving On" section is for college-age young adults.

### [www.cyh.com](http://www.cyh.com)

The "Young Adult Health" section of this website is designed for ages 18-25 and provides "information for young people on health issues, lifestyle choices and healthy relationships." *(The site is based out of Australia, so some of the resources are pertinent*

*to Australians only. However, the information provided and many of the links are helpful to anyone.)* Select “Healthy Mind,” then “Loss & Grief” for discussion of types of loss, grief, and tips to help deal with loss. This section includes answers to commonly asked questions about grief. Also has an extensive list of other health related links for young adults.

[www.campusblues.com](http://www.campusblues.com)

This comprehensive site covers just about anything a college student may experience. Sections include “Campusblues Forum,” for posting questions and discussing issues with peers; links to over 350 universities to help you find local college resources; general health issues, drug and alcohol information; and “Mental Health” with a section on loss and grief. A wonderful resource for a vast number of issues pertaining to the college student.

[www.counselingstlouis.net](http://www.counselingstlouis.net)

While “The Sibling Connection” website is dedicated to providing information to “anyone who has experienced the death of a brother or sister,” it provides valuable information for anyone dealing with death of a loved one and the bereavement process. The “college student” section is designed specifically for the needs of grieving young adults in their college years. It provides information on emotional support, college blues, loneliness, and caretaking, as well as four featured stories by other college students about their grief. Also, includes age appropriate links, movie suggestions and an extensive list of books.

<http://www.geocities.com/hotsprings/sauna/4424/index.html>

Designed for grieving young adults, “Losing A Parent...A Resource for Young Adults Coping” is a website created by Kaz, a young man who has lost both his parents. His site includes his story, others’ stories of parental loss, posted comments, memorials and poetry, and additional links.

[www.geocities.com/Athens/Forum/6811/yalp/](http://www.geocities.com/Athens/Forum/6811/yalp/)

“Young Adults Losing Parents” is another website designed by a young adult who shares the experience of losing a father and the subsequent lessons, feelings, and insights gained from that experience. Includes links, suggested books and music titles, and recommendations for coping.

[www.kidshealth.org/teen/](http://www.kidshealth.org/teen/)

This website is divided into sections for teens, parents, and kids. The teen section provides “doctor approved” information on a variety of health topics, including several resources on grief, depression, and anxiety. Although directed toward high school teens, older “young adults” will find the grief information helpful.

<http://rd4u.org.uk/index.html>

“Road for You” is a website designed by young adults, ages 16-25. The site claims to be for anyone 12-18, but will include posts from anyone up to age 25. This site has numerous links to other resources as well as grief information, timeline and story posts, and places to share feelings. A special “lads only” section is a chat room for young men. Although designed with teens in mind, this is a great site to explore.

[www.coolnurse.com](http://www.coolnurse.com)

Devoted to exploring a variety of health topics, this website is designed for teens and young adults. It offers grief information on “death of a parent” and “grieving friends” in the mental health section of the site map. These articles have links to similar articles. Additionally, this site offers a wealth of information on a variety of age-appropriate health and well-being topics.

[www.griefnet.org](http://www.griefnet.org)

This website’s focus is on-line support groups, divided by loss category. While not specifically for young adults, the different groups could provide support from others going through similar loss. The “library” contains numerous articles and book suggestions on grief.

[www.mysonsam.org](http://www.mysonsam.org)

This website was designed by Judy Fisher, a mother living in St. Louis who lost her 20-year-old son, Sam. While this site is dedicated to Sam, many of the sections are appropriate for anyone in grief. Topics include stages of grief, grieving differences, the feel of grief, being a friend to someone grieving, and help with grieving. The “Silencing the Mind” section is a wonderful resource for learning to meditate or pray through one’s grief. Includes an extensive list of suggested books on grief, meditation, and death.

<http://depression.about.com/gi/dynamic/offsite.htm?site=http%3A%2F%2Fub-counseling.buffalo.edu%2Fvpc.html>

By selecting the grief category, this site links to numerous articles about grief written for various university websites. Rather dry and academic, but informative.

Compiled by Beth S. Barrett, MSW  
Patient Services Coordinator  
The ALS Association, St. Louis Regional Chapter  
February, 2007

## BOOKS FOR YOUNG ADULTS

### BOOKS DEALING WITH ALS

*Tuesdays with Morrie: An Old Man, A Young Man, and Life's Greatest Lesson* by Mitch Albom. Publisher: Broadway, October 8, 2002.

- This best-selling book is the true story of a young man and his spiritual mentor, who has been diagnosed with ALS. As the older man is dying, he engages in a relationship with the younger man as he shares his insights and life lessons about living life to the fullest. A heartwarming and thought provoking read.

*I Remember Running: The Year I Got Everything I Ever Wanted and ALS* by Darcy Wakefield. Publisher: Marlowe & Company, August, 2006.

- The author relates the experiences and lessons of what she refers to as her "fast-forward life" after her diagnosis with ALS at the age of 33.

*Tales from the Bed: A Memoir* by Jenifer Estess as told to Valerie Estess. Publisher: Washington Square Press, 2004.

- This memoir is told by a young woman who is only in her thirties at the time of her diagnosis with ALS. With humor and grace, she relates the trials, tribulations and gifts of her battle with this fatal disease.

*I Choose To Live: A Journey Through Life with ALS* by William Sinton. Publisher: Banbury Publishing Company, November, 2002.

- This author recounts the story of his life with the diagnosis of ALS. His narrative is authentic, uplifting, and informative.

*If Only They Could Hear Me: A collection of personal stories about ALS and the families that have been affected* by Ed Rice. Publisher: BookSurge Publishing, December, 2005.

- A compilation of stories from families with a loved one living with ALS and their experiences, resiliency, and spirit.

### BOOKS DEALING WITH GRIEF

*Facing Grief: Bereavement and the Young Adult* by Susan Wallbank. Publisher: Lutterworth Press, August 1, 1997.

- Written specifically for the 18-28 age group, this book deals with all issues that face the young adult in grief. Topics include handling the funeral and legal issues to working through emotions and confusing feelings.

*Help for the Hard Times: Getting Through Loss* by Earl Hipp. Publisher: Hazelden, 1995.

- Easy to read, this book provides straight talk about what loss and grief are and how to work through them. Included are grief facts, journaling suggestions, creative exercises, and ideas for caring for yourself during your grief journey.

*Griefjourney: Notes of Grief for Teens, Young Adults and Anyone Who is Grieving* by Mark Scrivani. Publisher: Centering Corporation, 2004.

- Discusses the emotions of grief and the pain of holidays, saying goodbye, and coping. Includes information about how our love lives on and finding hope.

*You Can Get There From Here: Journaling Through the Grief, a Guide for Teens and Young Adults* by Leah Hawley. Publisher: Keuka-Saguaro Publishing, July, 2005.

- This book contains a program of journaling with a year's worth of thoughts, activities, and information in a format, designed specifically for the teen or young adult's interests and understandings.

*Healing Your Grieving Heart for Teens* by Alan D. Wohlfelt, Ph.D. Publisher: Companion Press, April, 2001.

- Written for teenagers, this book provides 100 practical ideas in helping understand, process, and move through the grief experience. Many of these activities and ideas are applicable to the college age student or young adult.

*Understanding Grief: Helping Yourself Heal* by Alan Wolfelt. Publisher: Accelerated Development, July, 1992.

- Written to address the issues of adult grief, the author uses the approach of the bereaved as an "active participant" in the grief process. Sections such as "Am I crazy?" and "What may I expect?" help normalize the emotions and experiences of grief. A special section on self-care encourages the bereaved to take time to process grief.

*I Will Remember You: What to do when someone you love dies; A Guidebook Through Grief for Teens* by Laura Dower. Publisher: Scholastic, Inc., April, 2001.

- This book is written for teens, but offers valuable insight, information, and activities for young adults, too. Each chapter addresses a different aspect of grief, offering "try this" exercises, personal stories, and practical suggestions for taking care of yourself as you move through grief.

*Grief's Courageous Journey: A Workbook* by S. Caplan and G. Lang. Publisher: New harbinger Publications, September, 1995.

- Written in workbook format, this book allows the bereaved to explore their grief through writing. Prompts and suggestions for journaling provide a step-by-step approach to working through the grief process.

*How to Go on Living When Someone You Love Dies* by Therese Rando. Publisher: Bantam, reprint July, 1991.

- An informative book about the grief process, encompassing many different scenarios of grief of a loved one.

*Beyond Grief: A Guide for Recovering from the Death of a Loved One* by Carol Staudacher. Publisher: New harbinger Publications, April, 1987.

- This book addresses the characteristics of grief as well as offers ideas for supporting yourself through the grief process with nurturing strategies and personal coping skills.

*The Next Place* by Warren Hanson. Publisher: Waldman House Press, 1997.

- This beautiful picture book describes a journey to a place where earthly hurts are left behind. The colorful illustrations and rhythmic poem will comfort the child in all of us.

For additional books on grief, look in the psychological section of the book store or type in "grief" for a search on [www.amazon.com](http://www.amazon.com). Many new and used books can be purchased on Amazon at a reduced price.

Also, two catalogue companies specialize in books and other print resources on grief. Their websites are: [www.compassionbooks.com](http://www.compassionbooks.com) and [www.centering.com](http://www.centering.com).

## Gone From My Sight

I am standing upon the seashore.  
A ship at my side spreads her white  
sails to the morning breeze and starts  
for the blue ocean.

She is an object of beauty and strength.  
I stand and watch her until at length  
she hangs like a speck of white cloud  
just where the sea and sky come  
to mingle with each other

Then someone at my side says;  
"There, she is gone!"

"Gone where?"  
Gone from my sight. That is all.  
She is just as large in mast and hull  
and spar as she was when she left my side  
and she is just as able to bear her  
load of living freight to her destined port.  
Her diminished size is in me, not in her.

And just at the moment when someone  
at my side says, "There, she is gone!"  
There are other eyes watching her coming,  
and other voices ready to take up the glad  
shout,  
"Here she comes!"

And that is dying.

~Henry Van Dyke