



Helping Hands

Welcome

Grief is the most common of all the issues palliative care must address. It is the single thread which runs through all illness and loss. Most obviously present after a death, its mark on the survivors, it is also present before a death: Families grieve in anticipation, and the dying person grieves as the end of her or his own life approaches. As we age or experience serious illness, grief accompanies the onset of new limitations to life, and to dreams. With so much opportunity to confront this singular suffering, one might think we'd know it well and find comfort in our understanding. But instead, many myths about grief persist, the most common being that we all grieve alike and within a certain time. As the articles in this edition of *Helping Hands* describe, grief is experienced differently at different ages, and uniquely in each individual's bereavement. One author, a child life specialist, appreciates the strength of a child who experienced the death of a parent. The other author, a psychiatrist, emphasizes the value found in life's hardest moments.

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Helping Children With Grief and Loss

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Whether you are talking to a child about death or about his or her parent having to face a serious illness, it is important to remember that what is happening to a loved one is affecting the whole family, including the children. But how much a child understands is dependent on the age of the child and what he or she can comprehend.

Lisa Ciarrocca

According to Swiss-born psychiatrist Elizabeth Kubler-Ross, author of the book "Death and Dying," there are stages of grief everyone dying goes through. While she focuses on the dying, experience suggests the grieving adult or child also experience death in stages: refusing to believe death is occurring; anger at God, loved ones or caregivers; asking for more time; feeling unable to bear the pain; and finally acceptance of death as real. For a child or adolescent, the reaction at each stage will depend on how the parent or other close adults respond.

Preschool children usually see death as temporary and reversible, a belief reinforced by cartoon characters who 'die' and 'come to life' again. Younger children believe they are the cause of what happens around them. A young child may believe a parent, grandparent, brother or sister died because he or she had once 'wished' the person dead. The child feels guilty because the wish 'came true'. In the later years of middle childhood, however, as youngsters are better able to understand the death and what caused it, they will be able to deal with it more directly. They may express their feelings about the death openly (through crying, for example), or in their play or daydreams.

It is important to remember that the loved one who has died was essential to the stability of the child's world, and anger is therefore a natural reaction. The anger may be revealed in boisterous play, nightmares, irritability or a variety of other behaviors. Often the child will show anger towards the surviving family members. After a parent dies, many children will act younger than they are. The child may temporarily become more infantile, demanding food, attention and cuddling, and talking 'baby talk'.

Confronting a death, parents or other adults are under a tremendous amount of stress, each with their own set of fears and uncertainties. Being honest with a child about illness and dying doesn't mean sharing all adult thoughts and feelings. Encourage and listen to the child's questions and answer simply. Share cultural and religious beliefs with a child and allow them to participate in what is going on around them.

Be aware of some obvious signals a child is in distress. Among these are persistently depressed mood, inability to sleep, loss of appetite, prolonged fear of being alone and withdrawal from friends or school activities. These warning signs indicate that professional help may be needed. A child and adolescent psychiatrist, psychologist, social worker or certified child life specialist can help the child accept the death and assist the survivors in helping the child through the mourning process.

In my 19 years of experience as a Child Life Specialist, I've learned a great deal from the children and families with whom I've worked, the most powerful lesson being that children are resilient. We worry a lot about how children will cope with change but they commonly do better than adults fear they will. I once worked with an eight year old who had just lost her mother to cancer. From diagnosis to end of life was only a year. Throughout her mother's illness I was there to accompany the child on hospital visits. I explained things as simple as why mom was hooked up to machines and intravenous lines to, more sadly, why her mom was unable to respond when the child spoke to her. Through the trust we had developed over the year, she opened up and asked many questions. I measured my answers by what she wanted to know and honored what she wanted to say or do.

I was amazed by the child's coping after her mother's death. She had found it hard to even walk into a hospital before her mother's illness but she was not the fearful, shy child I had met early on. She was more confident, could remember the happy times she and her mother had shared, and conveyed to others the wonderful things her mom had taught her. Throughout the bereavement, she supported her younger sister, explaining to her what was happening, frequently using words I had exchanged with her. Though she suffered a devastating loss, open communication and honesty had helped.

Suggested Guidelines Concerning Children and Grief

- Be a good observer. See how each child is behaving. Don't rush in with explanations. Usually, it's more helpful to ask exploring questions than to give quick

answers. Listen.

- When a loved one dies, don't expect children's reactions to be obvious and immediate. Be patient and be available.
- Children are part of the grieving family. Reassurance comes from the presence of loving people.
- When describing a death to a child, use simple and direct language.
- No one procedure or formula will fit all children, either at the time of death or during the months that follow. Be patient, flexible and adjust to

Helpful Websites:

www.compassionatefriends.com
www.flynnfuneral.com
www.aap.org/healthtopics
www.hospicenet.org

Helpful Books:

How to Help Children Through a Parent's Serious Illness, Kathleen McCue, Ron Bonn
Sad Isn't Bad: A Good-Grief Guidebook for Kids Dealing With Loss (Elf-Help Books for Kids), Michaelene Mundy, R. W. Alley
I Miss You: A First Look At Death, Pat Thomas, Lesley Harker
The Helper's Journey: Working with people facing grief, loss and life-threatening illness. Dale Larson, Dale G. Larson

New Support Program for Seniors

Overlook Hospital is offering a new free program for seniors which provides visits and services from a nurse and social worker with the goal of helping you continue to live independently and improve your quality of life. The program includes help monitoring your health and medications, links you to any needed community-based services, assists with advance care planning and provides your family and caregivers with medical, legal, nutritional, financial and safety information. You are eligible for the program if you are not currently receiving insurance-covered home care services.

For more information, call Ann Jessup, BSN or Lyn Renk, MSW at 973 921-8602 or email (ann.jessup@ahsys.org; elynor.renk@ahsys.org). This program is supported by the Grotta Fund for Senior Care of the Jewish Community Foundation of Metro West New Jersey.

On Grief

Peter Bolo, MD

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As a teenager, I recall being fascinated by Dr. Elisabeth Kübler-Ross' book, *On Death and Dying*; maybe this is why I wound up a psychiatrist instead of a banker or architect. In my work today, I find myself thinking back to her five stages of dying: denial, anger, bargaining, depression and acceptance. One thing I've learned in speaking with patients, however, is that grief is as individualized as a fingerprint, and that even a great theory like Kübler-Ross presented provides only an intellectual framework for understanding a truly personalized phenomenon.

Accepting and allowing one's own unique grief response – and accepting and allowing that of others – is key to navigating bereavement. There are no rules governing grief and no timeline. It doesn't end abruptly. One does not simply "get over it." And if anyone tells you that you should be done grieving or says, "It's time to move on with your life," they're just plain wrong. Such comments are well-meaning, but make the recipient feel worse; I suggest you nod politely and ignore them. And avoid repeating such things yourself.

When a loved one is facing a terminal illness, the grieving begins long before the moment of death. This poses a painful challenge and potential opportunity for rich communication and closeness, for the sharing of deep human emotional reactions – tears, regret, fear, anger, longing and others. Bereavement, as in all crises, is a time when channels of communication are opened and people grow closer. Unfortunately, bereavement may also be a flashpoint for destructive conflict. For many, it is easier to part in anger; it requires maturity, patience and hard work to separate in a loving and dignified manner. However, in the long run, it is worth the hard work.

People often ask me if their grieving is normal. If you've read this far, you can predict correctly that I reassure most that their own personal grief reaction is normal for them, that they are entitled to it, and to ignore those who suggest otherwise. I remind people that they need to take care of themselves while grieving. This includes eating properly and getting exercise and rest. I encourage people to participate in rituals such as funerals, memorial services and religious rites. For those who may be interested in sharing their thoughts and feelings, I mention local bereavement support groups or recommend a therapist, especially for those who are socially isolated.

If insomnia is a persistent problem, I suggest temporary use of a non-habit forming sleep aid. Likewise, intense anxiety or overwhelming emotionality may



Dr. Peter Bolo

benefit from conservative, time-limited use of anti-anxiety medication. Sleep deprivation and profound anxiety can be incapacitating and are of no inherent value in the grieving process; the benefits of a prudent, short-term, medically-supervised prescription to mitigate these symptoms typically far outweighs any risks. On the other hand, self-medication with alcohol and pills is dangerous and should be avoided.

Discerning an intense bereavement from an episode of major depression can be challenging. Both commonly share the following: persistently depressed mood; decreased energy, interest, motivation and pleasure; decreased appetite with weight loss; and insomnia. What is not typical of bereavement and more likely signals the development of clinical depression warranting treatment with psychotherapy and/or antidepressant medication includes: persisting suicidal thoughts or plans; intense feelings of self-reproach or diminished self-esteem; and delusions or hallucinations. If there is a prior history of major depression, bipolar disorder, or another psychiatric illness, bereavement is an important time to connect with a mental health professional for support and guidance. After all, loss is the most common precipitant of major depression and commonly triggers an exacerbation of a pre-existing psychiatric illness. Likewise, bereavement is an important time to connect with an AA or NA sponsor and to attend meetings if you suffer from a substance abuse disorder, as grief may trigger a destructive relapse.

Ultimately, grief and loss heighten our appreciation of life and add richness to our human experience. Bereavement is highly individualized with a broad range of normal reactions. It is a complex emotional response to which we are all entitled and which we all inevitably experience.

Bereavement Support Groups

For information on Bereavement Support Groups:

New Jersey

- Judith Manger, MSW, Bereavement Coordinator, Atlantic Hospice, (973) 379-8442. Groups are professionally facilitated, conducted throughout the year at various sites in the community, 5 to 8 sessions each, require pre-registration and are free of charge.
- NJ Self-Help Clearinghouse, (800) 367-6274, www.njgroups.org. This state-wide service provides an extensive database of information on peer support groups, some professionally facilitated, for every type of problem and condition, including bereavement.

National

- Compassionate Friends, Inc., www.compassionatefriends.org. This national organization provides peer support groups for families who have experienced the death of a child, information on the grieving process, referrals to local chapter meetings and a quarterly magazine.
- Growth House, www.growthhouse.org. This internet site has extensive informational resources on life-threatening illness, end-of-life care and grief and bereavement.