

The Aftermath of Loss: Guilt vs. Relief
By Beth Witrogen McLeod

For this relief much thanks. Tis bitter cold,
And I am sick at heart.

- Shakespeare

The confusing mix of emotions that follows in the wake of the death of a loved one sends us for a time into an unfamiliar landscape. We expect to be devastated; but when there is also relief, the paradox can bring on waves of guilt. And that can make it difficult to sort out the entire grief process. Although this mixed reaction of grief and relief is a normal one, it is hard to acknowledge, as if it means we haven't loved fully, or cared to our best ability. In a death-denying society, we feel ashamed and confused by these raw emotions, and worry that they are signs we are ill-equipped to handle profound grief. As end-of-life issues come out of the closet, however, the aftermath of loss is becoming a welcome exploration for bereaved caregivers, a way to understand this journey and make peace with it.

"We're a fix-it society: We like smiling faces and active, happy people," says Lee L. Pollak, director of The Bereavement Center at San Francisco's Jewish Family and Children's Services. "There's not a lot of room for the devastating sadness that comes with grief. There's a huge range of normal feelings that people experience when dealing with grief." Yet in a culture that doesn't do well with loss of any kind, that doesn't have social ritual that makes mourning an acceptable process, she says, "we don't do a real good job of saying good-bye to one stage before moving on." But willingness to move through the pain is one of the keys.

Cindy's Story

For seven years, Cindy Fowler, 50, cared for her mother with Parkinson's at home. During that time she worked full time as a graphics designer and helped launch the National Family Caregivers Association, while also balancing duties as wife and mother of three. Daytime home health aides took care of her mother while Cindy was at work; but at night, from the moment she walked in the door until her mother went to bed, she was on duty.

Cindy and her mother had a special bond, especially in the final years, when Cindy provided the most intimate care. She read to her mother at bedtime, they shared and reminisced, and when death came "it left an enormous hole - not only because we had a close relationship, but suddenly all of those tasks weren't there anymore." As well, the intense attention she was paying to her mother meant she was neglecting her own family, not intentionally but by not being as present as she needed to be. "They were understanding," Cindy says, "but none of us realized what [my caregiving] was doing to the family until it was over, when the marriage was in trouble and the kids were in trouble."

Cindy was struck by a "tremendous sense of freedom" after her mother passed away; although she felt like an orphan - her father had died long ago, and she is an only child - she also felt that she had substantially lost her mother to the disease years earlier. "I felt guilty - I felt I should be grieving, but mostly what I felt was freedom. I had a sense that this is my parent who had died and I loved her very much. I missed her, but I didn't miss the disease."

So many family issues had been percolating, she didn't have time to fully grieve the first year after her mother died. But now that her family is back on track, Cindy goes back into the grieving process "and am really struck by the loss of her. I try not to hide from those moments or put them away, but lean into them and experience them. I'm able to separate her from the disease now, and mourn the loss of HER." Revisiting the loss has erased Cindy's feelings of guilt; now this midlife passage is one of remembering their strong connections. "We didn't have any unfinished business; I'm really glad that I made the journey. It's an experience that I wouldn't trade for anything."

All of Your Feelings Are Perfectly Normal

Every year more than 11 million adults lose a parent: It is the single most common cause for bereavement in the country. Additionally, the U.S. News and World Report [Jan. 20, 1997] found that at the top of the list of stressful life events is the death of a spouse. Yet bereavement is a lonely business: It isn't socially sanctioned, so depressive feelings of sadness and emptiness, anger and guilt, are common - and isolating. We tend to make judgments about our own feelings, and that exacerbates our unease.

Caregiver grief usually begins before the actual death, as does the torment over wanting everyone's suffering to end. When everyone's suffering does finally end, relief actually is an appropriate response. But we often feel uncomfortable about this because what we have been taught is normal or acceptable behavior - what doesn't make waves in the mainstream - is different. Yet it is when we explore these edges that our lives can reshape themselves, using the mourning process as grist for the mill, enriching our lives with more heartfelt priorities and deeper relationships.

Grief therapist Alexandra Kennedy ("Losing a Parent," "Your Loved One Lives On Within You") says that what society labels as "psychotic or out of bounds is actually very natural in the grief state - and that grief is probably closer to the essence of what it is to be fully alive than what is seen as 'normal,' because we're feeling more; we're more fully authentic."

"It is perfectly appropriate to feel relieved at the same time you are feeling devastated," says Rabbi Earl A. Grollman in his "Decalogue: Ten Commandments for the Concerned Caregiver." In fact, he believes such emotions are well earned, both in feeling that an excruciating torment is over, and that we are ourselves no longer encumbered. Yet we are conditioned to have certain responses, and until we pay attention to them, it is hard to sort out what is real from what is not.

Catherine's Story

For four of Catherine Garda's seven impossible years of caregiving, she and her husband, Dick straddled the fence of uncertainty. His disease, a rare auto-immune disorder, would render him

completely bedfast for days at a time; then just as suddenly, he would go into remission. The roller coaster was unrelenting. While doctors were treating him he suffered a stroke and heart attack; then the disorder began affecting his nerves and moved into his organs. Dick's body was attacking itself. Catherine, who was 31 at the time, stood by her husband's side all the way.

"I was very fortunate in that in his mind, we were sick; it wasn't just that he was sick. In the first four years of his illness we kept thinking, and so did our physicians, that it would shut off, but we realized it wasn't going to happen and they started very aggressive treatments, including chemotherapy, transplant medication, a lot of steroid-type treatments, which brought their own side effects," she says.

The losses were both tangible and visceral as Catherine took over more responsibilities, especially John's last three years. "There were parts of my marriage that I lost - the ability to show affection, the ability to make love or show love in a tangible, physical way. I had to take over all the partnership aspects of our lives, so that partnership disappeared. It wasn't an illness - it was a menage a trois. Here I was not only responsible for taking care of him but was responsible for his life - what an incredibly difficult burden."

All the stages of grief were there, from crisis through loss, emptiness and renewal, a condensed and powerful tangle of emotions. When Dick died, he was only forty-five. But a grief observed has been very cathartic; Catherine has looked realistically at their relationship so that healing could take place. "We're all cautious not to speak ill of the dead and we're reared with that, but when we're trying to heal, we can't constantly put the person on a pedestal. There's one side of grief that gets you prepared for loss, but there's that devastation that we deal with, that 'what could have been/would have been.' The challenge was, I had lost myself, I had lost my identity. I didn't have any hobbies while he was ill, there was no time for me, so when he died I didn't have anything to do."

Catherine says that although her husband was a wonderful person and there was no doubt that she would always be with him, part of her grief process has been coming to terms with shadowy elements. "There are many qualities that I missed but many I didn't, and I was glad they were gone," she admits. "I'm also glad that my life could go on, because it was a personal choice to stay with him and care for him." Coming out of the intense loneliness of caregiving, Catherine has used bereavement as a process of self-rediscovery. "It's like getting to know an old friend. Some things I pull out and don't like to look at, but there's also, 'Oh wow, I remember this part of me!' It has been really exciting, like coming out of a fog."

Catherine began grief counseling to make sure that she was dealing with everything, including guilt over wanting her husband's suffering to end, that she had somehow brought on his death. "I realized I needed to deal with this darkness and get it out. I wanted to make sure I don't look back with regrets, that I get over any resentment about losing seven years of my life. That's been tough, but it's been good." Catherine has embraced her grief process with honesty and compassion. "Caregiving took its toll on me physically, emotionally, mentally and financially. It just eats at you every way it can, but you keep moving."

Today there are a lot of things that are the same, but I find I have a much different perspective as to what's important in life. I made a list of things that I always wanted to do, and I've been doing them, like ballroom dancing and SCUBA diving. I have a much better respect for the fragility of life, and I want to make sure that my priorities are really the ones I'd want to have, rather than ones someone else thinks I ought to have."

Moving Beyond Guilt

Grief work means work on relationships, and it often leaves us with a sense of unfinished business, feelings that were not expressed, forgiveness that was not asked. Caregivers are not alone in these gray emotions: Three out of ten people consulting a psychologist suffer from unresolved grief over a loved one's death, according to a 1994 survey conducted by the Jewish Funeral Directors of America. Yet no matter how much we have done as caregivers, it takes time to feel we did enough, especially when we were trying to balance our complex of roles.

In her book on widowhood, "I'm Grieving As Fast As I Can," Linda Feinberg defines "death guilt." And she counsels: "Widowhood is the time to be kind to yourself and not be your own worst critic". Some of the thoughts and feelings associated with death guilt include:

- Torment over not having done or said everything you wanted;
- Feeling you could or should have done more, even controlling the dying process;
- Discovering you are more accepting of the death and grief becomes less intense;
- Smiling and laughing after the death;
- Guilt because you were not overly fond of the person anyway.

Phil Garrison, a hospice and respite professional for 15 years, has observed that it's hard for most caregivers to recognize, let alone talk about, resentment over having to be the responsible one 24 hours a day. "And then they feel guilt, or worse yet, shame, for their sense of relief when the loved one dies. Recognizing resentment/relief as part of the emotional fabric of caregiving is an important first step to ensuring a healthy recovery from the losses. It is the honest recognition of life as changed by the experiences of living with suffering that empowers people to grow through the process of grieving the death of their loved one."

Gordon's Story

As impossible as it is to lose a parent or spouse, the death of a child comes in reverse order, and throws a life upside down. The grieving process can become deeply complicated, but with time there is softening, synthesis. "I never expected to bury my first-born son," wrote psychiatrist Gordon Livingston of the death of his 22-year-old son, Andrew, who committed suicide after a three-year struggle with bipolar illness.

Inconceivably, a further blow hit him and his wife, Clare, not long after when they learned that their six-year-old son, Lucas, had leukemia and a narrow chance of survival. During the six months that the family endured multiple hospitalizations, fevers, a bone marrow transplant from Livingston himself, chemotherapy, a hopeful remission and endless salvaging of hope and faith, Gordon kept a journal [The San Francisco Examiner Magazine, November 8 and 15, 1992] into

which he poured his questions about life and death, and the injustice of the sufferings of an innocent child. "The way he has dealt with this awful illness and its treatment has struck everyone who has cared for him as exceptional - the love and elemental goodness that he exudes," Livingston wrote.

When Lucas died, after more pain than any parent could bear to watch, the parents were inconsolable. Gordon wrote of his vulnerability to feelings of jealous bitterness watching other families, wondering if he could ever be happy again. The fact that his own marrow was not enough to save his child, let alone the incredible bond they shared, wracked him with grief, especially the guilt that the disease that killed his son came from his own body. And even though Lucas never complained, never got angry at the unfairness of it all, still his father found some measure of relief believing that his two sons were reunited, safe in heaven.

Although Gordon continually mourned the loss of his relationship to and future with Lucas, when he visited the grave site he felt surprisingly peaceful and hopeful, sensing that regret and loss would not always be the overriding emotions - that all the images of his son endlessly bound to machinery in the hospital would be replaced with more joyful memories. "Already the sadness and anger we feel at your not being alive are changing to good thoughts about all you gave us in your short time on earth," Gordon wrote of the importance of transforming his feelings of self-pity into courage. "I do not need God's forgiveness; I need my own."

We Grow as We Grieve

The process of grieving is individual, and it marches to its own seasons. The land mines of memory are everywhere: Certain foods or songs, grocery shopping, birthdays and anniversaries, selling a home. They keep us periodically vulnerable, never far from the pin pricks of experience. But it is during these intense times that greater possibilities emerge. "There is great strength gained through the process of facing grief," says Massachusetts General Hospital geriatric social worker Daniel Paris. "It is integral to our growth and development as human beings." For where there is relief, there is not always guilt, but love.

After a time, many caregivers can look back and discover many gifts in the journey they undertook, especially knowing that they gave so much love and good care under the most trying of circumstances. They move back into life in a new way, wiser and more patient, with a renewed sense of faith in the tenacity and courage of the human heart. Grief becomes companion rather than enemy, a reminder of the preciousness of relationship.

Ruth's Story

Ruth, 66, cared for Betty, 73, her partner of 28 years, intermittently from 1983, when Betty was diagnosed with breast cancer, then metastatic tumors to her hip and back in 1985. The two social workers lived fully, taking a bicycle trip to Europe, golf, RV trips, Elder Hostel, but in 1992, Betty began various chemotherapy treatments and needed more assistance. Ruth says it was hard to watch Betty become dependent on her - to get out of bed, to the commode, to get dressed.

"But I believe that for all of her fight, being bed bound [after a fall] was where she drew the line," Ruth says of the night she died. "I was numb, lost, and very alone the first few weeks after Betty's death, but shortly also became aware of a great weight lifting off me, a gradual reduction of fear, depression and strain: Relief which I initially wondered if I should or would feel guilty about."

As Ruth dealt with her acute feelings of loss, she tried to figure out what the relief was all about. The reasons included that Betty was no longer in pain, even though Ruth could keep her relatively comfortable; that she had not had to tolerate being bed bound any longer; that the actual process of dying had not scared her; that they had been able to maintain a close relationship in the midst of anger and helplessness.

"My training [as a medical and geriatric social worker] suggested that I would feel guilty about the experience of relief right along with the pain and loss," Ruth says, "but I did not. I mentioned it to the hospice nurse and she said a lot of people feel guilty about feeling that way. I do feel guilty about petty things I did or did not do or say as her caretaker and partner, but the feeling of relief after she died has seemed acceptable."

Healing

"We haven't failed at life if we are unhappy for a time," Lee Pollak says. "Grief is like being in winter; caregiving is like being in the fall, knowing that winter is coming. Healing is being able to feel a range of emotions, able to acknowledge there is sadness and pain that will come up at different times - and there is also joy and happiness. Incorporating a full range of emotions: That's what healing is."

Beth Witrogen McLeod is at work on "The Heart of Caregiving," to be published by John Wiley & Sons in Spring 1999.