

Why Isn't It Easier?

by Beth Witrogen McLeod

Carol still remembers her caregiving days clearly: Her husband Don, a dermatologist, was confined to a hospital and ICU unit for nearly two years with liver disease. She was the only family caregiver, spending twelve hours a day there with him, every day. "I was just as much a patient as he was" she recalls. I did go home every night but I was back with him every day, and there were plenty of times I was called in the middle of night. I went to church and choir practice and kept Don's practice going with the help of military physicians, but it was like a wall closing in on all sides. I suffered from severe anxiety.

Carol, who is a registered nurse, understood the machines that kept her husband alive, as well as the medical discussions, but that didn't lessen the anxiety, especially because she and Don were in Pittsburgh, where his chances for a liver transplant were greatest, and their two 20 something sons were on their own in Memphis.

They were married just shy of 24 years when Don passed away; that was 11 years ago. There was no grief support in those days; "grief was something you did almost in silence," Carol says.

She had tried to be in control, tried to remain strong, but it took its toll. Even after 10 years, says Carol, now fifty-six, long-term caregiving has changed her life. "Grief comes in waves, rather than suddenly like a Mac truck hitting me. The waves are further apart, but you never know when they will hit. If I hear a song and it brings back a memory, I can always switch a radio station. But thoughts can be hard to control."

Signs of complicated grief

Grief and mourning are more supported today than in recent years as death and dying issues are coming out of the closet. Yet we still feel embarrassed and ashamed by these powerful emotions, anxious that if we are not always smiling and "well-adjusted," there is something wrong with us. Although death is a universal experience, we have a very different experience of it today because most of it occurs not in the home, but in a hospital or other institution, says Andrea Sankar, author of "Dying at Home" (Johns Hopkins University Press, 1991). We are conditioned to return to business as usual, to "get over it" and "get on with life." But sometimes that doesn't happen easily; sometimes the feeling of deep loss can go on for years.

How do we know when our mourning is within reasonable range, or when it has become dysfunctional and needs to be addressed? "Too long" depends on the person and who they've lost, as well as the duration and intensity of caregiving, say professionals. And, hard as it is to lose a spouse or parent, losing a child is a different circumstance in that so much of the future is forever

altered.

"Complicated grieving" is well known to therapists who specialize in bereavement. Intense, early feelings of confusion, loneliness, wanting to die, and experiencing embarrassment or discomfort in expressing grief are some signs of this intense process. Grief can cause a variety of feelings, all of which are to be expected. Sometimes, however, it is prolonged, and it is at this juncture of "chronic mourning" when time alone may not be enough to complete the healing.

Indications of complicated grief include: guilt that can't be shaken or that grows into self-hate or self-destructiveness; unrelenting anger or hostility; increased use of drugs or alcohol; inability to carry out daily tasks or take on responsibilities several months after the loss; suicidal thoughts or feelings of worthlessness; unrelenting loneliness; panic attacks; the inability to feel anything at all.

"Certain situations, like multiple loss or severe trauma, may predispose people to complicated grief," says Roz Leiser, a registered nurse who leads Moving Through Loss & Transition workshops, based on principles taught at the Elisabeth Kübler-Ross Center. "The path of grief is not a period of time, but a process. You can't put a definition on a certain amount of time after which there is no problem. People grieve through different stages. When it becomes a problem is when there is NO process, when people are going over and over the same things. There is no change in what is experienced or expressed over a long period of time. Dysfunction is when there's no movement, when people can't express anything and are stuck."

Sandy was only forty when she lost her young child, Mikey, to leukemia . After four years, she still could not find any meaning in life. Her husband wanted another child, but she was unwilling; eventually, they drifted apart and divorced. Even today she has pictures of Mikey all around her house; she is back to working part time, but is unable to enjoy her colleagues or their children because of the pain she always feels, especially about being a failure as a mother and a wife. She thinks that if she had been more attentive, smarter ... she doesn't know what. But she cannot let go, and she cannot stop feeling sorry. It has been more than six years.

"Sometimes people can't let go of grief because they equate it with letting go of that relationship," says Leiser. "It becomes an incredible emotional confusion: 'If I stop grieving I don't care about them or it means they're really gone. If I'm crying every day, I'm still connected to them.'

Long-term mourning means there's usually some aspect of relationship with the deceased person that is unresolved, experts say. It can be anything: guilt over something that happened years earlier, or a feeling that as a caregiver you didn't do enough, or feelings of anger. "Anger is a common part of grief that people can't acknowledge," adds Leiser, "because there's a social stigma against being angry or speaking ill of the dead. So often, people become very angry - or even carry it from childhood - and never work it through with the person. Yet those feelings remain, even after the

person is gone, and we think we should only think nice things about this deceased person."

Author Hope Edelman ("Motherless Daughters," Addison-Wesley, 1994) says that after her mother died at 42, her family avoided discussion of the loss "and pretended to pick up exactly where we'd left off. In that first year we continued with the routines of schoolwork, vacations, and bimonthly haircuts as if a central family member were so dispensable that her absence required only a minor reshuffling of household chores. Anger, guilt, sadness, grief - all emotions were suppressed, shooting out like brief bullets only when we couldn't contain them anymore."

Edelman says that only 13 years later did she begin to make sense of the devastating toll that her unresolved grief had taken: an unrelenting sadness, a lack of a role model for later years (she was 17 when her mother died of cancer), feeling stuck in her emotional development, someone tainted or marked as different. The loss of her mother had become the focal point of her identity without her even realizing it. Only when she began to discover other women who had been secretly mourning mother loss for many years did she come to terms with the full impact of unresolved grief.

Other adult children who have lost parents have difficulty resolving grief because of unfinished business. Monette had distanced herself from her parents in her teens; when she was 50, both her parents died within a short time. Now she is overcome by depression because she sees how much time she lost with them, how much she blamed them for her failures and unhappiness. She thinks about what might have been, and cannot get beyond the fact that she never accepted them for who they were even though she demanded that they validate her every move. Now there is no chance to know them, and she cannot find a way to forgive the selfishness of her younger days.

From loss to acceptance

On the road from denial to acceptance are many pitfalls, and many signposts. Clinical psychologist Dr. Therese Rando, director and founder of the Institute for the Study and Treatment of Loss in Warwick, R.I., says that complicated mourning is defined as "...some compromising failure or distortion of one or more of the processes of mourning identified as necessary to healthfully accommodating a loss."

These processes include: recognizing the loss; identifying with the loss and giving it some form of expression; identifying and mourning both tangible and intangible secondary losses, such as companionship, connections to a social group, or a notion of the way the world is supposed to be; reviewing and remembering the deceased and the relationship realistically; relinquishing the old attitudes to the deceased, as well as the old world view; readjusting to moving adaptively into the world; and developing a new relationship with the deceased.

Rando says that especially for long-term caregivers, there are a number of things that may

predispose them to complicated mourning, such as the nature of the relationship before the person became ill. She also identifies post-traumatic-type stress as a factor in lengthy mourning: "I argue that having a loved one die from a life-threatening illness exposes us to circumstances that will elicit post-traumatic stress responses. These can contribute to some difficulty after death - they need not necessarily, but they certainly can, if they're not attended to." The trauma of witnessing a long-term dying process can complicate mourning, drawing it out over time - unconsciously but very palpably.

In "How to Go On Living When Someone You Love Dies" (Bantam, 1991), Rando discusses losses of an adult sibling, a parent, a child, a spouse. In her practice, she has found that chronic mourning seems to persist interminably and doesn't draw to a natural conclusion, so that the intense reactions go on over time: The bereaved never gets past the stage of acute grief.

"The processes of revision and readjustment never occur," she says. "For these people, it's just as if they lost their loved one days before. For some people this affords a kind of connection with the deceased, and is used as a way to get an identity as a mourner, which gives gratification. The mourner is stuck in this initial response and never gets past it."

Some mourners, she says, prefer to stay in this place rather than make changes and go on without the deceased, preferring an obsolescent world - especially when there has been great dependency. "It doesn't always have to happen, but we see it as coming from a 'disorder of attachment' - they don't think they can go on in the absence of the individual, so they just hang on to the old world even though things have changed."

Barbara Cohen exhibited the classic signs of an inability to finish grief after her husband of fifty years, Marvin, died after a ten-year battle with emphysema, diabetes, and congestive heart failure. The primary caregiver for most of those years, Barbara retired early from her career as a paralegal to care for Marvin full time. Though they had sufficient money to finance more in-home help, and even a nursing facility when he became totally dependent, still she felt it was her duty as a wife and a woman to tend to all of his needs. For the first year after Marvin died, Barbara rarely left the house. Ashamed of her intense emotions and unable to cope with widowhood, she spent most of that time in bed.

"I never understood what was normal in the grief process," Barbara says now, five years later. "I was constantly judging the process or suppressing it, so that I would feel in control. I felt that to be strong, I couldn't express my sorrow. No words could describe the total disruption in my life that the caregiving caused; but even more was the high level of grief that permeated every day."

Caught in limbo between past and future, Barbara felt nothing but emptiness in the present. She could not accept Marvin's death, and therefore couldn't begin the mourning process. Because she was the first among her circle of friends to lose a spouse, no one understood what she was going

through. In her isolation she felt abnormal, which further suppressed her ability to express her grief. She wallowed in unresolved feelings of guilt, such as worrying that she hadn't gotten him to the doctor early enough, or often enough; she compiled a laundry list of hurts and grievances that she dwelled on alone. Unable to move forward, she remained stuck in fear that her grief would never end, and that she hadn't enough courage or smarts to live without Marvin. Afraid that opening to the pain would cause an explosion of unbearable emotion, she chose instead to face the other direction until one day she awoke realizing she was wasting her own precious life.

"Pain, loss and separation can lead you to growth," says Rabbi Earl Grollman, author of several works on bereavement, "or they can destroy your life. Death brings you this choice. Grief changes you, but it is not destroying you. Grief is a powerful teacher."

Things you can do to Help get Through the Grieving Process

- *Mobilize a social support system as soon as possible. Talk through feelings rather than dwelling on them. Try to see a new perspective.

- * Identify potential coping difficulties early in the grief process. Seek professional help if you feel stuck.

- * Develop rituals to give a sense of beginning and ending. People of the 19th century had constant reminders of death and willingly became familiar with it: They would take daylong family outings to cemeteries to remember the departed. They were expected to do this; they wanted to do this.

Hospice bereavement consultant Sue Shaffer says rituals lend structure and support, like a road map. Cultural and religious traditions can provide formal patterns of behavior to guide people during confusing and chaotic times of transition. There can also be formal or informal, private or public rituals that happen once or regularly to give expression to powerful emotions. These might include visiting the grave site, reading old letters, creating a public memorial, even tears.

"People have to have some way to express what they've experienced, to acknowledge it," says Leiser. "There's not one right way. There needs to be some way, however, to fully express the whole range of relationship to the person. Some people do that through journal writing, some through a memorial service."

- * Acknowledge grief for things other than death; for caregivers it's important to recognize the smaller losses and changes in relationship even as the illness progresses. This "invisible grief" manifests when a loved one dies and can be a complicating factor if not made conscious. When feelings are expressed, they cannot become so overwhelming. And you won't be left wishing for what might have been.

*Keeping all your relationships current. Leiser says treat people as if this might be the last time you ever see them, even if they're not sick. "Tell people what you need to tell them; if there's some problem, address it. Then you will have no regrets, because you never really do know."

Life goes on

Therese Rando says that many people believe that mourning continues forever; but it is acute grief that eventually ends. "A person may be long past acute grief yet still be in mourning," she says. "Even long after a death, a wide variety of circumstances can produce brief periods of acute grief for the loss of the loved one."

"Accommodating the loss will leave a psychic scar similar to a scar that remains after a physical injury. This scar does not necessarily interfere with the mourner's overall functioning, but on certain days and under particular conditions it may ache or throb and require some attention. Healthy accommodation does not mean that the mourner no longer mourns. It means only that the person has learned to live with mourning in ways that do not interfere with his or her ongoing healthy functioning in the new life without the loved one. Accommodation centers on learning to live with the fact of the loved one's absence, moving forward in the new world despite the fact that the psychic scar caused by the loss remains and, on occasion, brings pain."

Carol took a cruise four months after Don died, but began to realize how exhausted she was. By the second year things were still horrendous; by the fifth year she could see progress in feeling better. The 10th year has been her best since Don's death. She just kept pushing her way very slowly into the world. She has remained in her church choir, has taken up gardening and singing in a symphony chorus, joined a neighborhood sewing club, and until recently maintained her husband's practice. She began dating someone a few years ago, and although they live 150 miles apart, they share many activities, including Greek studies. She is also a facilitator in a church group of widows.

"For a long time I had no identity. I had trained, worked hard, entered the race and gave all my worth and at the end I never knew what happened. After four months and four years I still felt like half a person when my husband died. It would have helped knowing it was OK to just be and feel crazy. I was alone and I am sure those going through this now feel they are the only ones, too."

"Death of a loved one leaves us different, and the missing of the loved one is always there. It just gets to where it does not hurt so much. Someone told me it takes one year of recovery for every three years of marriage. It is almost 11 years and I can honestly say all of us just now have come to terms with everything. There is a world there, it goes on. You either join in and try to love again, or you will never get over it."

Christine Longaker, author of "Facing Death and Finding Hope" and lecturer on spiritual care of the dying, writes that even two years after her husband's death, the cycles of intense pain and

sadness were xcruciating. Although she wanted to ignore each intrusion of fresh pain and hopelessness - even contemplating suicide - she finally addressed her feelings of grasping, of longings that could never be satisfied. Wanting her life back, she decided to practice a new way of thinking about her greatest loss. "I am letting you go and wishing you well," she began gingerly. "I am going to survive and be strong. I am going to make a new life for myself." And after a few months, she discovered that her process of mourning felt complete.

"Part of the task of mourning is to let go of our former relationship and then consciously decide to create a new life, with meaning and purpose," she writes. "This decision helps us summon the courage to finish our grief. Failing this, mourners can end up living halfheartedly in a shadow world, grievers needs to find their own personal answer to the question: For what purpose will I continue to live?"

Beth Witrogen McLeod is a freelance writer. She lives in California, Her book, "Caregiving: The Spiritual Journey of Love, Loss, and Renewal," will be published in spring 1999 by John Wiley & Sons.