Who Am I Now That I Am Not a Caregiver?

By Beth Witrogen McLeod

For all of his eight years, Carolyn Piskura cared for her little Billy, a hydrocephalic child who was ventilator-dependent and had a seizure disorder. He also had a stomach tube, thyroid problems and brittle bones. Mentally he remained at two or three years old. Carolyn was able to have 16 hours of nursing care each day through a state waiver program, but Billy could never be left alone. Caregiving was intense; he was critical most of his life.

After Billy died last year, Carolyn discovered she had lost herself, because for so long her sole responsibility had been her son. Her identity was caught up in mothering and caregiving. Afterward, she wasn't sure who she was, although she knew she was not the same person. "As a caregiver, you feel like you're not yourself. I was always 'Billy's mom' or 'Mrs. Piskura.' I was rarely ever Carolyn. It was tough to find Carolyn again."

Caregiving means not only taking up new duties, it also means a new identity. Especially long term, this role often takes precedence over other relationships - employee, wife, friend, artist, son, daughter. Because they've been crowded into a corner for so long, these other relationships, other identities, may not get enough attention to stay strong. And when our loved one is gone, we are left for a time on a threshold between these roles, not fitting into old patterns and not ready for new activities. In this phase of bereavement called "reorganization" - where we also experience numbness, searching and despair - it is important to recognize how much of our lifestyle and patterns have already changed, and what direction we want to go now.

Caregiving is a transformational process, and its aftermath demands that we take care of ourselves and be patient until we become fully alive again. But there are steps we can take, and signposts to help us along the way.

Carolyn, 36, says it took her a long time to come back to herself. Although she has returned to work as a licensed professional nurse in high-tech pediatrics and now has a healthy three-year-old son, Danny, the transition has been a struggle. "During those eight years it was difficult to maintain friendships. Billy never had a prognosis; so we never knew -- two years, five years, 10 years -- we could lose him at any time. You never felt like you could give too much to friends because the priority was always the child."

Carolyn has regained her life by meditating, doing a lot of reading, and pursuing her career. She is able to work with families in similar care-intensive situations, and she brings an added dimension of compassion because of what she's been through. She's joined Weight Watchers to take off the sixty pounds she gained after Danny was born, and feels she has her life again.

“Everyone has to travel their own path. We all grieve in our own time and space.” To that end, she has picked a favorite picture of Billy – out of thousands - and had it miniaturized so she could wear it every day in a special pendant necklace. "For years I had to keep up a facade because of Billy. Looking through all those photos, I was finally able to cry and let go. The pendant, with his name and dates inscribed, is a nice way to remember him, " she says.

Losing ourselves

Caregiving involves so many losses along the way, yet none is as shocking as the actual death of a parent, a spouse, a child, a dear friend or relative. We have invested well in these relationships, built so much of our lives around them, that when they are no longer an active part of our lives, we are left with a gaping hole. It is in that space we grieve, for we have lost a cherished part of ourselves. But it is also in that space that we sow the seeds of our new lives.

"You bury it so deep," says Janet Fasanaro, who cared for her husband of fifty-two years, living his life for him, losing her own in his Alzheimer's. She let Ray do for himself as long as he could. He never stopped moving, so neither did she. Then he became incontinent, and she was responsible for his whole life.

"I became him. I lost myself completely in those two years. You're going crazy, you know what it is but still you can't detach from it. We were locked in the house together, and I guess I started to have a nervous collapse. I took excellent care of him. But I could not get myself back for a long time after his death. It was like a breakdown - you don't know how to live, you don't know how to think straight. Your own life means nothing at all; you don't care if you live or die. I would look at people and think oh, they're living, if only I could live that way. I dedicated my life to him, and this was a part of my marriage."

Alan D. Wolfelt, director of the Center for Loss and Life Transition in Fort Collins, Colo., calls the idea of getting over grief a myth. "Everyone is changed by the grief experience," he says. "For the mourner to assume that life will be exactly as it was prior to the death is unrealistic and potentially damaging. Recovery is all too often seen erroneously as an absolute, a perfect state of reestablishment."

He prefers the term "reconciliation" to define what occurs as the caregiver integrates the new reality of moving forward without the physical presence of the loved one. "As the experience of reconciliation unfolds, the mourner recognizes that life will be different. Beyond an intellectual working through is an emotional working through. What has been understood at the 'head' level is now understood at the 'heart' level." Then, he says, commitments to the future can be made.

The fruitful emptiness

This period of working through is a fruitful darkness, according to anthropologist and Buddhist scholar Joan Halifax. After her mother died, she says, the abrupt severance transformed "the stream of routine into a river of sorrow. As she had been severed from me, I severed myself from my ordinary life." She was torn apart by huge emotions. Yet it was in that loneliness that she examined her dark feelings and crafted a new life, one that was accepting of all emotional and psychological cycles and seasons.

One of the most important steps in processing our grief is to examine the barriers to recovery: Guilt, anger and regret are three of the biggest. Before new life can be enjoyed, these emotions must be given their due. This means an adjustment in how we view the world and ourselves: We

can no longer depend on old ways to see us through new territory. Likewise, we cannot expect others to always understand what our loss means. Caring for a frail loved one through unspeakable sorrow has shifted our way of being in the world, and of seeing ourselves. We are more vulnerable but also more courageous and competent than we ever knew, which means that our relationships will change. Family dynamics and friendships will probably undergo some reorganization. Not all changes will be negative by any means; but these "secondary losses" need to be acknowledged. We do this alone or we do this by sharing, but it is critical to our healing that we do it somehow, so that our new life can take a shape that is worthy of the life passage we have just gone through.

Rose and Emmett were married 45 years; he passed away last September, after emphysema, heart failure and two bypasses. "My grief comes in waves and a few times it comes in tidal waves," Rose says. "Like when I found a note from him telling me how much he loved me and knew I loved him. He was in a nursing home when he died. We had planned on him being at home. I regret not being able to take care of him those last few precious days."

Rose went into a grief recovery group at her church last November, thinking it would help; it was for all types of loss. "Losing a brother, a sister, son, daughter, mother, father, is not the same as losing a spouse," she says. "There was a man that was just unhappy with his life, and no one cared about him. That was sad, but it didn't help my hurt. There was a lady that had lost her 20-year-old daughter to a drunk diver three years ago. I felt very bad for her, but that didn't help my hurt." And so Rose decided the group was not for her. (Some people in grief, as well as in caregiving, find it hard to relate to people whose circumstances aren't exactly the same as theirs. It is important to know whether you are such a person, so that you can more easily find the help you need.)

"We were so much in love the last few years that it is so hard to lose him," Rose says. "Now I don't have anyone to care for. I miss getting him his ice water, taking care of his medications and making sure he took them. My sister says I am a caring person that almost needs to be needed."

This feeling of having nothing of you left after being a caregiver, is an important signpost to recovering a whole life. Says grief counselor Alexandra Kennedy ("Losing a Parent," "Your Loved One Lives on Within You"), caregiving is a time "full of intense emotion because you're dealing with dying and archetypal events. Then after the death there is a letdown. You have this incredible sense of having been part of something so big and something so precious that in spite of the fact that it's taken every ounce of energy, afterward, everything is gone."

Loss of relationship is at the center of the grief experience, especially the loss of identity of being a daughter, son, spouse, or parent. We also lose our identity in the world, our stability, health and vitality, dreams and hopes and friends. As we redefine who we are after caregiving, we need to come to terms with what has been lost, and what has been gained. It is a normal process, although Western society would prefer smiling faces. How we handle it will lay the foundation for how we return to the world.

"It is natural to feel overwhelmed, out of control, to have all this feeling coming up," says Alexandra. "The big question is, how do you allow grief to happen so that you can have healing

at the same time? You have let go of work and put relationships on hold during caregiving, and suddenly you have to go back to ordinary life. There is a real sense of letdown, of 'Who am I now?' when I was part of this very important thing that was happening."

"We live in a culture where we don't deal well with the unknown," she says. "We tend to want to get away from it. It is difficult to allow for that sense of space rather than trying to fill it up right away. There's a lot of pressure from jobs and friends and spouses to spring back to who you were, but you've changed, now you're carrying grief, and it's a difficult time ahead."

Coping strategies

Cyndi, 43, has lost her father, grandfather, and two grandmothers in the last three years. "I knew life was never going to be the same. Losing someone is like having my life packed away in a nice neat suitcase, and all of a sudden someone comes in and dumps all my things out and I have to repack. Only to find out everything no longer fits, and may never quite fit the way it has before. Loss continually makes me repack."

Now that caregiving is over, other relationships demand to be released from the corner and given attention. Spouses and children, employers and friends, all expect us to return to "normal." But life is not the same; it can never be. We need to consider what roles we want to assume or regain, how we now see ourselves in the world. And that takes time and energy.

Coping strategies include activities as necessary as taking care of household, legal and financial matters, to shopping for new clothes or having a bath by candlelight. Grief counselor Martha Felber ("Grief Expressed") suggests little steps: walking to regain stamina, checking for good posture, making a list of short- and long-term goals. It is easy to feel overwhelmed by all that needs to be done; caregivers find themselves unable to focus, spending hours watching television, taking longer shopping than is needed for a particular list, she says. Yet this is all part of grief. Eventually there will come a time when certain business is completed, and the caregiver can consider closure: honoring the life shared, so that the new one can begin.

Self-care is critical to managing grief. When we have no one else to care for but ourselves, it can be difficult to re-establish routines. Yet the discipline of physical exercise, of good nutrition and diet, can begin to take up those spaces that caregiving used to fill, and lay the foundation for what is to come, Felber advises. Caring for oneself with time and patience also helps relieve depression and anxiety, and helps move the caregiver beyond loss. Some people begin writing in journals to sort through their emotions, to clarify their problems and goals. This can help you cling less to memory and illusion, and begin the process of healing.

Moving on

Because there are so many unfamiliar emotions that come up through caregiving - especially because of changed priorities - caregivers go through a lot of changes, even if they don't recognize it at the time. They feel a little out of time and place: It is hard to fill up a life again with people who have not been through what we've been through, who have not faced the hard issues of aging and illness and death. Urged on by a need to live more simply or authentically,

former caregivers might end marriages, quit jobs or get involved with causes to help relieve suffering. Many volunteer for community and religious programs, such as giving respite to other caregivers or visiting nursing home residents, becoming mentors and companions. They make lists of things they've always wanted to do and then start doing them. Widows and widowers start dating again, easing back into social life more appreciative of what life has to offer.

For some former caregivers, the period of regaining a sense of self can push them in an entirely new direction. Carol Walton, 52, has taken her mandate all the way to Capitol Hill in the years since she looked after her father, who died of Parkinson's disease in 1993. Once a long-distance caregiver, she had to move him five times in seven years to different levels of assisted living because of the progression of the disease and her lack of awareness of resources.

At the time, Carol didn't know a lot about caregiving, but was always doing the best she could. Afterward, however, she was left with a burning desire to push for changes in health care and Parkinson's research. Her understanding of what families go through, and the bewilderment of handling difficult behaviors, led her to form a consumer action network and organize caregiver education and leadership training. Then in1994 she moved into the congressional arena. She gathered sponsorship for the Morris K. Udall Parkinson's Research and Education Act authorizing a fourfold increase in spending for Parkinson's research at the National Institutes of Health -
$100 million a year for four to five years. The measure passed in November 1997. Now she is working on the appropriations segment of the bill as well as organizing a task force comprising the four major Parkinson's organizations.

Although for a time she didn't know what she would do with her life, she followed her heart. "Everything happens for a reason. I didn't believe that my father had this disease for twelve years for nothing, but it was for me to figure it out. So many powerful, positive things have come out of this experience; it's rare to think back now about how bad it was. Some people never understand what their gifts are, and how to use them. I'm really honored - there's nothing like this."

The Gift of Life

Alexandra Kennedy suggests that taking time daily to allow "the sense that your hands are empty and there's nothing more to do" is the most important first step in filling out a life after caregiving. Sanctuary, as she calls the quiet time alone to be with grief, gives time to explore inevitable changes in values, questioning what matters, and working out any unfinished business we may have had with the deceased. "Grief is a transformational process that makes possible huge shifts in who you are. You emerge so much bigger than who you thought you were, but you won't get there if you don't go through the feeling that you've lost yourself. It is a very delicate time; the identity builds again very, very slowly on all the emotions that are surfacing through grief. Are you willing to sit long enough for this new identity to emerge, or grab at the first thing because it's so uncomfortable, you want to fill it up? If so, you sell yourself short.

"It's okay to feel empty and alone and to not know who you are and where you're going. A lot of people don't realize the opportunity - all of this feeling is overwhelming. But you begin to build the seeds of a new life from all this emptiness. You really do emerge back into life with some sort of idea or creativity that is seeking to be expressed. It's a place that is so much fuller because it embraces so much more of life. It's almost as if our loved ones, in their deaths, give us the gift of life - again. And it's our choice if we take it, the second time."

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