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Caregiving: The Spiritual Journey of Love, Loss, and Renewal

Beth Witrogen McLeod
Articles

My parents' deaths left a double-edged legacy: awareness of both the generosity of the human heart. Nowhere perhaps is this played out than on the daily stage of family caregiving, where caregivers can find themselves on a chaotic journey in which the only option is the demise of their loved one. These caregivers are on a path seemingly subjected to the stresses and guilts of watching another's pain, unable to erase it, witnessing a loved one's dying without being able to help. They quietly sacrifice personal agendas to look after those in need, sandwiched between child care and jobs, and usually without support. They live a world apart from everyday reality and wonder if they will ever be normal again. They have one goal: to maintain the dignity and care of their loved one until the end. The burden is great, the information overload, and doubt overpowering. Yet these loyal souls - many of whom do not see themselves as caregivers - work largely without professional help and must do everything alone. There is no question about taking care of them. They do so compelled not only by the dictates of society, but by the love of the heart.

They bathe, feed, dress, shop for, listen to, and transport frail children, friends, relatives, neighbors, and even strangers. Nightmares torment over how to keep loved ones out of nursing homes, how to get adequate medical attention and make life-and-death decisions. Many have not been trained to do so. Often in poor health or over age sixty, they worry about safeguarding an obstinate relative's finances and moving her to a more secure home.

One of the biggest health care crises, say doctors, psychologists

workers, is the depression faced by those who minister to aging friends - sometimes for decades. More than sixty percent of caregivers experience depression; the figure is higher among those who care for those with dementia. Women suffer more than men: As many as two-thirds experience clinical depression, which often requires medical intervention. The emotional jeopardy: We anguish over what has happened to our loved one and over what is being required of us. We want to be good caregivers but often feel so inadequate and exhausted that we become unable to continue.

The tentacles of depression reach far and wide: into work and family finances and health. Emotions build on waves of disability, frustration and unpredictability to loss of identity and lifestyle. It is hard to do a good job when our loved one only continues to deteriorate. The task becomes personal: Rather than accepting it as a medical condition beyond the scope of a lay person to control, caregivers feel it is they themselves who have lost control and is inadequate.

Many caregivers report physical or mental health problems; working caregivers are most at risk. Despite the many positive aspects of caregiving - the clear satisfaction in solving difficult problems, devotion and keeping a loved one at home - these acts of love are time-intensive, and emotionally binding. Sometimes there are simply not enough physical, emotional, or financial resources to carry out our intentions. It is a realistic means that we cannot always understand, predict, or control. That does not mean we have failed.

When caregiving becomes more stressful than satisfying, when exhaustion, irritability, disturbances and an inability to leave the loved one become chronic, caregiver burnout ensues. One of the greatest sources of depression among caregivers is "compassion fatigue," an inability to continue, over the long term, the commitment and fulfillment of the early days.

Studies have shown that the best predictor of institutionalization of the family to maintain the older person at home, rather than hospitalization, is the exacerbation of the medical condition. As people live longer and require more assistance, caregiver burnout is increasing: Many people survive conditions that would have killed them years ago and choose to remain at home, which requires a twenty-four family involvement.

Those at highest risk -- especially people caring for loved ones who are frail -- experience great loss, ill health, and depressive illness - traits that are common in the caregiving orbit.

And yet, if the loss is shattering enough, the disillusionment of the call [to spiritual growth] is heard from within, says clinical psychologist Elisabeth Kubler-Ross. Some may refuse to respond. Those who listen will enter a new phase of life.

place, a symbolic death of the old ways. Yet a foundation of n
from this depth.

If we close our hearts to suffering, we cannot open them to lo
benevolent act counts. By surviving difficulties and holding o
caregivers inspire others to summon the power of the spirit. I
emerge from violence and carelessness into an enlightened ag
the lessons of grief will be honored, exemplified by modern-d
fulfill the age-old mandate: to give.

Beth Witrogen McLeod

Beth Witrogen McLeod is an author, journalist, speaker and c
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Her expertise grew out of personal experience caring for her p
simultaneously terminally ill 1,200 miles away. With a father c
of cancer and a mother with Lou Gehrig's disease and demer
learned firsthand about the traumas and blessings of this mi
passage. She turned her experiences into a passion for public
writing and producing an award-winning newspaper series, "
for The San Francisco Examiner in 1995. It was nominated fo
She developed a weekly column for The Examiner that often
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Hospice Organization, Pew Charitable Trusts, American Legio
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