My parents’ deaths left a double-edged legacy: awareness of both the sorrow and the generosity of the human heart. Nowhere perhaps is this paradox more widely played out than on the daily stage of family caregiving, where the unsuspecting can find themselves on a chaotic journey in which the only certainty is the demise of their loved one. These caregivers are on a path seemingly without end, subjected to the stresses and guilts of watching another’s pain without being able to erase it, witnessing a loved one’s dying without being able to prevent it. They quietly sacrifice personal agendas to look after those in need, often sandwiched between child care and jobs, and usually without advance planning. 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 well-being of their loved one until the end. The burden is great, the information insufficient, the doubt overpowering. Yet these loyal souls - many of whom do not recognize themselves as caregivers - work largely without professional help, feeling they can and must do everything alone. There is no question about taking on this role: They do so compelled not only by the dictates of society, but also the mandates of the heart.

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

One of the biggest health care crises, say doctors, psychologists, and social workers, is the depression faced by those who minister to aging relatives and friends - sometimes for decades. More than sixty percent of caregivers experience depression; the figure is higher among those who care for loved ones with dementia. Women suffer more than men: As many as twenty percent report clinical depression, which often requires medical intervention. It is double jeopardy: We anguish over what has happened to our loved one, as we are shaken by what is being required of us. We want to be good caregivers, but after a while feel so inadequate and exhausted that we become unable to care at all.

The tentacles of depression reach far and wide: into work and family dynamics, finances and health. Emotions build on waves of disability, from powerlessness and unpredictability to loss of identity and lifestyle. It is hard to feel we are doing a good job when our loved one only continues to deteriorate. The disease 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 are out of control and inadequate.

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

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

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

Those at highest risk -- especially people caring for loved ones with dementia -- experience great loss, ill health, and depressive illness - traits commonly found in the caregiving orbit.

And yet, if the loss is shattering enough, the disillusionment deep enough, the call [to spiritual growth] is heard from within, says clinical psychologist Connie Zweig. Some may refuse to respond. Those who listen will enter a dark but holy place, a symbolic death of the old ways. Yet a foundation of new life is poured from this depth.

If we close our hearts to suffering, we cannot open them to love. Every benevolent act counts. By surviving difficulties and holding onto goodness, caregivers inspire others to summon the power of the spirit. Humanity can emerge from violence and carelessness into an enlightened age of caring when the lessons of grief will be honored, exemplified by modern-day heroes who fulfill the age-old mandate: to give.

Beth Witrogen McLeod

Beth Witrogen McLeod is an author, journalist, speaker and consultant on caregiving, end-of-life issues and renewal at midlife, especially for women. She is a double Pulitzer Prize nominee, and has won many national and regional awards for her work. She has written for Good Housekeeping, SELF, Family Circle, and The Wall Street Journal, among others. Her latest book is Caregiving: The Spiritual Journey of Love, Loss, and Renewal www.Witrogen.Com

Her expertise grew out of personal experience caring for her parents who were simultaneously terminally ill 1,200 miles away. With a father dying of a rare form of cancer and a mother with Lou Gehrig's disease and dementia, McLeod learned firsthand about the traumas and blessings of this mid-life rite of passage. She turned her experiences into a passion for public service, first writing and producing an award-winning newspaper series, "The Caregivers," for The San Francisco Examiner in 1995. It was nominated for a Pulitzer Prize. She developed a weekly column for The Examiner that often appeared on the New York Times Syndicate Web site. Honors for the series included National Hospice Organization, Pew Charitable Trusts, American Legion Auxiliary, Society of Professional Journalists, and many regional and local social service organizations.


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