

Moving On

By Beth Witrogen McLeod

Most caregivers willingly and lovingly take on the duties that are required of them, either suddenly or over the long term. They give their all to ensure that their husbands, their parents, their children or other loved ones go through critical or chronic illness, even death, with as much dignity, compassion, and independence as possible.

For many caregivers, devoting oneself so completely can become life-transforming: The trials of faith and compassion cannot be ignored. More often than not, these caregivers discover an irresistible imperative to find meaning in both the difficulties and the triumphs and to share the wisdom of experience with others who follow.

The end of caregiving marks a stage in life, both an ending and a beginning. Moving on involves using hard-wrought lessons in new ways: re-establishing priorities, coping with grief more softly, and refocusing on what truly matters in one's own life rather than chasing after society's dreams and expectations.

One of the hardest lessons caregivers learn is letting go; yet in each release, healing is possible. "Letting go means allowing the one who has died to leave and continue on her journey," writes Victoria Frigo in "You Can Help Someone Who's Grieving". "To achieve healing, the grieving person will need to 'let go' again and again in many different ways. Be aware that these last good-byes are some of the hardest things a person will ever do."

In this separation, it is possible to see the caregiving experience from a different perspective, producing a greater sense of peace and a vision of the greater whole in which we live. The pain, anger, guilt, resentment and fear that we may have experienced while in the depths of caring for our loved ones is given a chance to dissipate, to be forgiven, by taking even one step back. This distance, however small, allows us to see our roles -- our gifts and our problems -- with more realistic insight and nurturing.

"While I was a caregiver," says Myrna Block, a single mother who lost her young daughter to leukemia, "all I could see was the two of us. Now that she has been gone two years, I can see that everyone suffers in some way, that we all go through experiences that make us more human. It was very healing to understand the connections that we have even in the worst of times. I am no longer alone in my grief, and know that I can move on and still have a meaningful life, even though Karen can never be replaced."

The Wisdom of Experience

Perhaps the most important lesson of caregiving -- the one that lasts a lifetime -- is the capacity to open the heart even in the midst of suffering, to accommodate and integrate change as a fact of life.

"Loss, grief, and mourning are three inevitabilities of human existence encountered often throughout life," says clinical psychologist Therese A. Rando, director of The Institute for the Study and Treatment of Loss in Warwick, R.I. "Although typically associated with death and other traumatic events, they are actually inherent aspects of all change, whether it is perceived as positive or negative. To the extent that a caregiver can identify the elements of loss in a human experience and can respond to and facilitate the attendant grief and mourning, the caregiver possesses knowledge and skill fundamental to intervention in every human condition."

No matter what form a caregiver's new life will take, the one certain element is a new vision of, and respect for, the process of aging. No longer subjected to the restrictions and values of a culture that celebrates youth over the wisdom of age, most former caregivers feel that growing older is a time to find authenticity and purpose in a whole new way. It is a chance to recommit to life, to renew dreams and reconnect with others in the most fulfilling relationships.

"Aging is not happening automatically as it did in the past -- by people simply getting older," says Theodore Roszak, author of "America the Wise". "In an overwhelming number of cases, people enter old age through a medical crisis, which is becoming like a rite of passage into one's older years.

"That ordeal teaches you something. It brings you as close to death as you can come. If you don't come back from an experience like that more philosophical than when you went into it, then nothing's ever going to change you. Somebody who no longer has to worry about raising a family, pleasing a boss, or earning more money will have the chance to join with others in building a compassionate society where people can think deep thoughts, create beauty, study nature, teach the young, worship what they hold sacred, and care for one another."

His hope is that people will use medical crises and suffering to transform themselves into deeper human beings who find life's meaning in kindness. "My hope is that crises would make people ask what really matters in life: not money, but kindness; not winning, but loving. People would come out on the side of compassionate values."

Extending a Hand Back and Planning Ahead

It is this new found compassion that compels many former caregivers to give of themselves in new ways, small and large. When they are ready, caregivers often become hospice volunteers, visit residents in convalescent facilities, advocate for more funding for community resources, and join on-line chats to help relieve suffering and confusion. They volunteer in church programs for elders or help families with special needs children; they teach classes on caregiving; they organize brown-bag lunches at work or push employers to institute elder-care benefits. They create Web sites, develop newsletters, join local and national health organizations, and lobby the media to cover long-term care issues.

Using what you have learned often blossoms into a desire to help others. Timid and isolated during caregiving, today many caregivers have risen above their hardships and become voices for others who are still in the midst of great challenges. They are messengers of caring, giving support

where they can and creating new ways of sharing expertise.

For Tom Scott, the frustration and anger over the problems his parents had with Medicare and health-care providers spurred him to develop special software for families to demystify Medicare paperwork and help track providers and payments.

For Carol Walton, seven years of long-distance caregiving for a father with Parkinson's disease propelled her into the arena of congressional lobbying. She successfully helped push through a bill that will greatly increase funding for research for Parkinson's through the National Institutes of Health.

For Karen Sue Karle, caregiving for a deeply religious mother with Alzheimer's inspired her to develop a special program called First Saturday, whereby ill loved ones can attend religious services with their caregivers despite incontinence, frailty, or disability.

For Irene Pollin, a social worker in Bethesda, Md., losing an infant son and a teenage daughter to a congenital heart problem led to an epiphany: She developed Medical Crisis Counseling, a therapeutic process in which trained therapists work with chronically ill patients and their families to help them overcome the psychological problems often associated with illness and caregiving. In addition, she established the Linda Pollin Foundation in her daughter's memory to teach mental health professionals how to help families caught in the web of chronic illness, and she has also authored two books on overcoming the challenges of long-term illness.

Former caregivers also ensure that their children won't go through what they did: They do estate planning and have family meetings while they all are still healthy, using what they have learned to benefit the next generations. "Planning early is one of most important things we can do," says certified financial planner Wendy Wanger. "It has the potential to eliminate family conflict and prevent financial disasters down the road." Many older caregivers who don't want their children to be burdened are setting up living trusts and updating wills and beneficiaries. They are consulting professionals such as financial planners, elder law attorneys and funeral directors to make sure that all documents are in order, especially while everyone is healthy and able to participate in making decisions.

"I don't want my children to take care of me, not at all," says Claudine Michael, whose adult children live nearby. "I would never put them through what I went through caring for my husband." That included two aortic aneurysms, bladder cancer, and fibromyalgia, effects that last today with erratic blood pressure and a compromised immune system. Claudine has made sure that her pension, Social Security and life insurance will cover any unforeseen circumstances such as nursing home placement. She wants her children to have their own lives, a feeling echoed across the board especially on Internet chat groups.

Becoming a Mentor

By learning from their own experience and creating programs to help others, in these and many other ways, former caregivers become mentors to those just beginning or even well on their way along the caregiving road. They are able to look back on what they've experienced, seeing the pain

from a bit of distance and charting a new course. Life is no longer about the pain and frustration, but the memories and a need and desire to reconnect with others, to smile again and to recognize that they are different, tested by the fires and having survived great odds.

The National Family Caregivers Association (NFCA) wants to help foster this new way of being by inviting you to become a member of its new Mentor Program, an extension of its Bereavement Program.

When you become a mentor to others, you continue to build a group of people who care about others and who are committed to bringing awareness to long-term care. You continue to help families who don't know as much as you do. Most of all, you continue to reinforce the best of what humankind can offer: compassion, connection, and community. Those who have heeded the call to care for ill or disabled loved ones are in the best position to guide others in this life passage; they are the ones who have opened their hearts to suffering, and measured up to seemingly impossible demands. They know the way through the emotional labyrinth; they are the best guides, because they have survived beyond imagining. Through courage and perseverance, through untold acts of love despite great obstacles, family caregivers are at the forefront of a new kind of volunteerism and advocacy that cannot help but make this country, this world, a kinder place to live. This is no small tribute to our loved ones who have died.

NFCA is issuing an invitation to all former caregivers, to reach out and give back to those still embarked on the caregiving journey. You can be a mentor, a friendly "hello" on the phone, the voice of experience and therefore comfort to a caregiver who needs encouragement, advice or support. Your commitment means volunteering to be available by phone or e-mail to a small number of current caregivers at least once a month, and to allow them to get in touch with you during times of special need. The level of the commitment is up to you. Even a little bit of your time will make a difference. As you move on and create a new life for yourself, we hope you will want to create a legacy of love from your caregiving experience. For more information on how to become an NFCA Mentor call 1-800-896-3650 or e-mail us at: info@nfcacares.org.

Beth Witrogen McLeod's book, "Caregiving: The Spiritual Journey of Love, Loss, and Renewal," will be published in April 1999 by John Wiley & Sons.