

Refueling Time: It's Okay to Just Give to Yourself
By Beth Witrogen McLeod

[ital] We live forward, we think backward.

Kierkegaard

For a full year following my parents' deaths -- five weeks apart, in a nursing home 1,200 miles away -- I fell prey to clinical depression. I didn't know it then, didn't realize how, by never taking time for myself during two intense years of caregiving, I was heading for emotional and physical breakdown. Riddled with fatigue and apathy, I could find no meaning in the suffering, no way to reconcile that I hadn't been able to do more, to do enough -- to pull them back from the brink and save them.

IT TAKES TIME

I lived a year of survivor's guilt, afraid that if I enjoyed myself I would betray their love and dishonor their pain. I had spent so much time not thinking about myself, I was afraid to even try. I bought into cultural conditioning that we should get back to business as usual, and quickly, so as not to make waves or burden others with expressions of grief. And so I became an island unto myself, despite a wonderfully caring husband, believing that I was weak to feel whole again. While I was caring for my parents my life had meaning; now I no longer mattered. I could not give to myself; I simply did not feel deserving. I also didn't know what I needed or wanted.

After the first anniversary of my parents' deaths, somehow the clouds began to lift and I understood that I was going through a normal life cycle, a

passage not marked by Western culture but more common as we become a nation of caregivers. Whether we are grieving the loss of a parent, a spouse, a child or good friend, there are common stages we pass through, often more than once, as we move from the exhaustion and despair of caregiving, through the numbness and shock of the death itself, and into healing and reclaiming our lives.

A FERTILE DARKNESS

"I didn't get my life back together -- I created a new one," says Tommye, who lost her mother, then her husband of 40 years, and her job of 25 years -- all critical changes in a short time. "I was wrapped in caregiving with my mother over long distance while I worked full time and drove the 1,200 miles every six to eight weeks -- never realizing that my husband was literally dying before my eyes. When one's eyes and heart are focused in one direction, one rarely sees what is happening around them."

Tommye lost her lifetime career, her lifetime relationship, her entire style of living. "Such a devastating loss requires new structure in one's life, possibly new friends, and more than likely a new career direction." Yet, believing she needed to remain "strong," her emotional, religious, physical and mental worlds imploded. She fainted on the streets of New York City and couldn't remember her children's names, their phone numbers or even where they worked. She knew she could get home, but afterward, her comeback was a slow process.

Caring for a loved one, especially over a long time and under intense

situations, can strip away the expectations and lifestyles around which we built our self-esteem and identity. We are left for a time in a limbo that may seem bereft but which is actually a fertile darkness, a time of healing and rebuilding that allows us to take stock of our lives and refuel for the future. It is a time that may feel barren and mysterious, but it is also a period just for ourselves, when our focus can return to what we need and want, in order to discover new purpose, to honor the love we have lost by returning to the world as caring, contributing people.

ATTENDING TO THE YEARS OF NEGLECT

Most caregivers suffer degrees of sleep deprivation, denial, isolation, disruptions in eating and exercising and working. Appetite and energy and interest in daily activities may have fallen by the wayside. There are many feelings a bereaved person may have experienced, such as anger and resentment and guilt; there may be physical fallout such as constipation and indigestion, skin rashes, weight loss, tightness in the chest, palpitations, nausea or prostate problems. In this "letdown" time that follows the ordeal, it is likely, experts say, that these aftereffects will demand attention -- so that fresh reserves of stamina and engagement can be built.

"It seems like I'm more tired than I've ever been," says Janice, voicing a common caregiver predicament. She is only 40 but has cared for both parents and an aunt over four years. "It's been three years since I've seen a doctor for my personal being, except for my mental health, as I'm currently seeing a therapist and psychiatrist for depression and anxiety."

Especially in a society that emphasizes achieving, caregivers pay the price for doing too much and not looking after themselves. Then, when they can let down, they often feel guilty about doing so. Friends, family, colleagues may not want, or be able, to accompany us through this limbo, where nothing feels anchored but where we are regenerating. Without mourning, however, we cannot move out of the pain and into new life, which is the goal of all life-changing events -- and what our loved ones would wish for us. This is a time of nesting, says life planning consultant Frederic M. Hudson, a time to move from "doing" to "being" tasks. "Cocooning begins with grieving, a purging of the complex lifestyle that you were immersed in and a move toward simplicity. It cannot be rushed. As with the healing of a deep wound, time must pass," he says, "and new personal resources must be found."

"During the time I was a caregiver, I was diagnosed with fibromyalgia and severe deep-sleep apnea," says Carol, 56, a retired registered nurse who cared for both husband and mother at different times. Her husband had been a longtime diabetic who abused his health; five years after they married, he had a massive coronary and died.

Two years later an aunt who had been known for her immaculate nature was found to be near death from malnutrition and a lung infection secondary to allergies and vermin in her home. Neighbors had reported that she was collecting garbage and storing it in her apartment; there were bugs and

mice everywhere. Carol, who hadn't been fond of Lola, stepped in nonetheless and grew to love her deeply.

But both episodes took their toll. "The need to care for her kept me going until she died but after that I became almost immobilized by the pain of fibromyalgia, and it got worse before it got better. I was barely able to get around on crutches," Carol says, understanding that she got into trouble because she refused help. "Caring for both of them was more physically and emotionally exhausting than I realized until it was over but I don't regret doing it. If the need arose I would do it again, but right now it is time to take care of me."

BEREAVEMENT IS HARD WORK

Carol's refueling has come not only through taking care of her physical problems but especially through examining her emotions. "Looking after yourself during bereavement is more than just a matter of staying rested, fed, and healthy," writes Edward Myers in "When Parents Die" (Penguin Books, 1997), "but treating yourself well in these ways is a necessary start. In addition, you must give yourself some emotional leeway. Don't expect too much too soon. Bereavement is hard work, and often long work as well."

This is a time to assess negative feelings and to disarm them so they are no longer enemies. "Grief and anger are disabling," says Dolores, a psychologist who lost her 21-year-old son to a drunk driver, then her daughter-in-law and 12-year-old granddaughter who were shot by a burglar

who broke into their home while they were sleeping. "We had to move on -- move on to be thankful to have had our loved ones as long as we did. We had to heal and move on to take comfort and joy in the happy memories."

A psychologist, Dolores offers these common-sense rules for the healing process (in "After the Darkest Hour the Sun Will Shine Again" by Elizabeth Mehren, Fireside Books, 1997):

- * Talk about the feelings of loss and pain.

- * Take medication under doctor's monitoring if sleeplessness is a problem.

- * Keep as close as possible to a normal schedule of sleeping and eating. Eating is often difficult, but it is important at this time to focus on good nutrition. Alcohol is a depressant.

- * Enjoy fresh air, exercise and light ; sitting in a dark room can bring on depression.

- * Accept hands that reach out to help.

- * "Talk" to the deceased or write them letters.

Many small activities can free up energy that has been trapped in sorrow, in maintaining the past. We can redeploy this energy to build strength, to

rest, to revitalize and clarify life's purpose and focus. It is not that the mourner should not think about the past; it is that there must be a difference between dwelling and indulging, and forgiving and accepting. The former keeps us paralyzed; the latter propels us forward. Health can be damaged by the unrelenting stresses of caregiving, and too often we have no control; yet during bereavement, when the demands of immediate caregiving have ceased, we have an opportunity to take charge of our well-being.

MOVING FORWARD

English research psychiatrist Colin Murray Parkes says that "the more I study bereavement, the more convinced I become that transcending grief -- coming through the process in a healthy way -- is a growth-promoting experience, however painful it may be, in the vast majority of people."

After her big losses, Tommye felt that she no longer belonged anywhere or to anyone. But she realized that caregiving had made her resourceful, flexible, ready to try new experiences. "There is no way you can piece together the old life," she says. "The part of you that made up the old life has gone, along with all the creature comforts that went with it. You have to create a new life -- by finding new adventures, people and experiences that please you. You have to learn to recognize memorable moments, and seize them as tiny seedlings which hopefully will flourish into bigger and better things." Most of all, she says, it is important to find support.

Many former caregivers join relationship specific support groups ie widow/widower, caregiver chats

and national bereavement organizations that allow people to have one-on-one, group or on-line support for their questions and concerns. Hospice also offers yearlong follow-up bereavement support, which can allow caregivers to express their feelings in a safe environment. These are some supports that give credence to the final stages of bereavement: acceptance and hope.

After rest and recuperation, Tommye started out by volunteering at a local hospital as a secretary in the chaplaincy. She greeted new patients in the cardiac ward, reassuring them they would be okay. Then she extended her volunteering to the financial department, went into on-line chats and joined a widows group, one of which she now leads for AARP.

Holistic nurse practitioner Joan Furman says that a person reaches the stage of acceptance when he or she begins to take an interest in life again. "When this happens, it may be accompanied by a feeling of betrayal as you move farther away from your loved one. Acceptance does not imply forgetting your loved one or the relationship you shared. It is the slow but sure recognition that you are still alive and can go on living." And with acceptance comes hope, because we are beginning to feel good again. It is both consolation and promise; it indicates that we are coming into our own.

No matter what form refueling takes, it is important to arrive at an understanding that it is not only okay to take care of oneself, but that it

is critical to do so. For this is a time of healing, not just of body but also of emotions and mind. Finding your own voice, your heart's desire, learning to forgive others -- and fate -- paying attention to the ways you have not listened to your inner needs: These are the tasks that inform bereavement. "Healing is the foundation for self-renewal and the rebirth," says counselor Hudson. "When you are healed enough to look ahead, you move along the cycle of change. And the mystery is that the healing has not merely bound the wounds; it has transformed the cocoon into a new person."

HOW TO REFUEL

What kinds of activities revivify us? They can be large or small. Refueling can mean a new job or career, retirement, divorce, moving or selling a home; it can also be, as Martha Felber discovered after the loss of her husband, putting the cherry back on top of the grapefruit. She realized she was worth that treat, and began to discover many other things she had been denying herself, special activities she had done with her husband. So she started making her bed again, going for a drive on a pretty day, brewing coffee instead of settling for instant, making pancakes and new recipes just for herself, and going out to dinner with a good book.

To work through feelings and begin building a new foundation, Shell Krager, who contributes to the on-line Medical Support Bulletin Board (www.erichad.com/grief/grief11.htm), suggests writing a memorial to your loved one (poem, sentence, book), drawing or painting a memory, dancing your feelings, crying, tackling a huge cleaning job. Wendy Sikorra advises going to the park or mountains and sitting among the trees, or to the beach

and watching the cycles of waves. Other suggestions: movies, friends, naps, bubble baths, music. If you need, make a daily checklist -- including brushing your teeth -- to get you through the worst of times. Know that as time passes, however, you may wish to renew hobbies or start new ones. "Just learning to focus on one thing for short periods can be very therapeutic," a former caregiver says.

The ability -- and the desire -- to go back out into the world, albeit a different world without our loved one, is one of the surest markers that we have given back to ourselves enough to have a foundation for new life. "It is the sense of knowing you've done the right thing," says Val, who cared for her father for several hard years, financially and emotionally. Her son was born a year after her father died. "It's so wonderful to be involved in a life just beginning after going through so many lives ending for the last few years ... the never-ending circle of life."

LOVING LIFE AGAIN

It can also be said of caregivers: that new life is always within reach, if we have the willingness, the patience, to allow it to happen. If we are rushing to make life the way it used to be, to fill in the discomfort with old patterns, we will end up disappointed, because that life no longer exists. Facing grief, healing from loss, means that we have taken the time to understand that death is a part of life, and not something we need feel guilty or confused about. Healing also means that we have come to understand, respect and give to ourselves, that taking care is not a selfish act.

Refueling means learning that you can cope, the pain does lessen, that much of what you feared did not come to pass and life does go on. You cared, you became involved, you sacrificed interests and dreams, and you are a better person for it -- the gifts you have given cannot be measured or counted.

And even though you have experienced unfathomable loss, you met it with more courage and strength than you ever imagined, and you have survived. Now you can learn to thrive -- a lifelong process. This is a chapter that's never been written. Relationships will be restructured, you will build new skills, you will continue to experience loss and letting go. But now you have the secret that is shared in compassion: whether to be a victim or to live fully.

"The most important thing to keep in mind is that you will almost certainly go through the grief process without harm," says author Myers. The human organism can not only withstand the stresses of loss but often prevails over them as well.

Says Tommye: "I cannot believe how exciting life is becoming, more and more each day. Life, even without Bill, has become very challenging. I can hardly wait to see what the next day will bring."

Beth Witrogen McLeod's book, "The Heart of Caregiving," will be published in Spring 1999 by John Wiley & Sons.

