

# The Job No One Asks For

by Jon Caswell

**T**alk about a job nobody asks for — caregiving is a thicket of opportunities for physical and psychological exhaustion. Even when done willingly and with love, it is rife with guilt and depression. The physical toll on caregivers can be staggering — back problems, heart disease, depression. Then there is the anger that comes from feeling victimized by another person's disease — anger that is often suppressed because of the guilt it brings up. Add to all that the fact that no one is ever completely prepared to take responsibility for another's life, no matter how much they love them. Caregiving is a big job, and it has a high cost. In money alone, the National Family Caregivers Alliance estimates that family members provide more than \$257 billion of services. But that is only the tip of the iceberg in terms of cost.

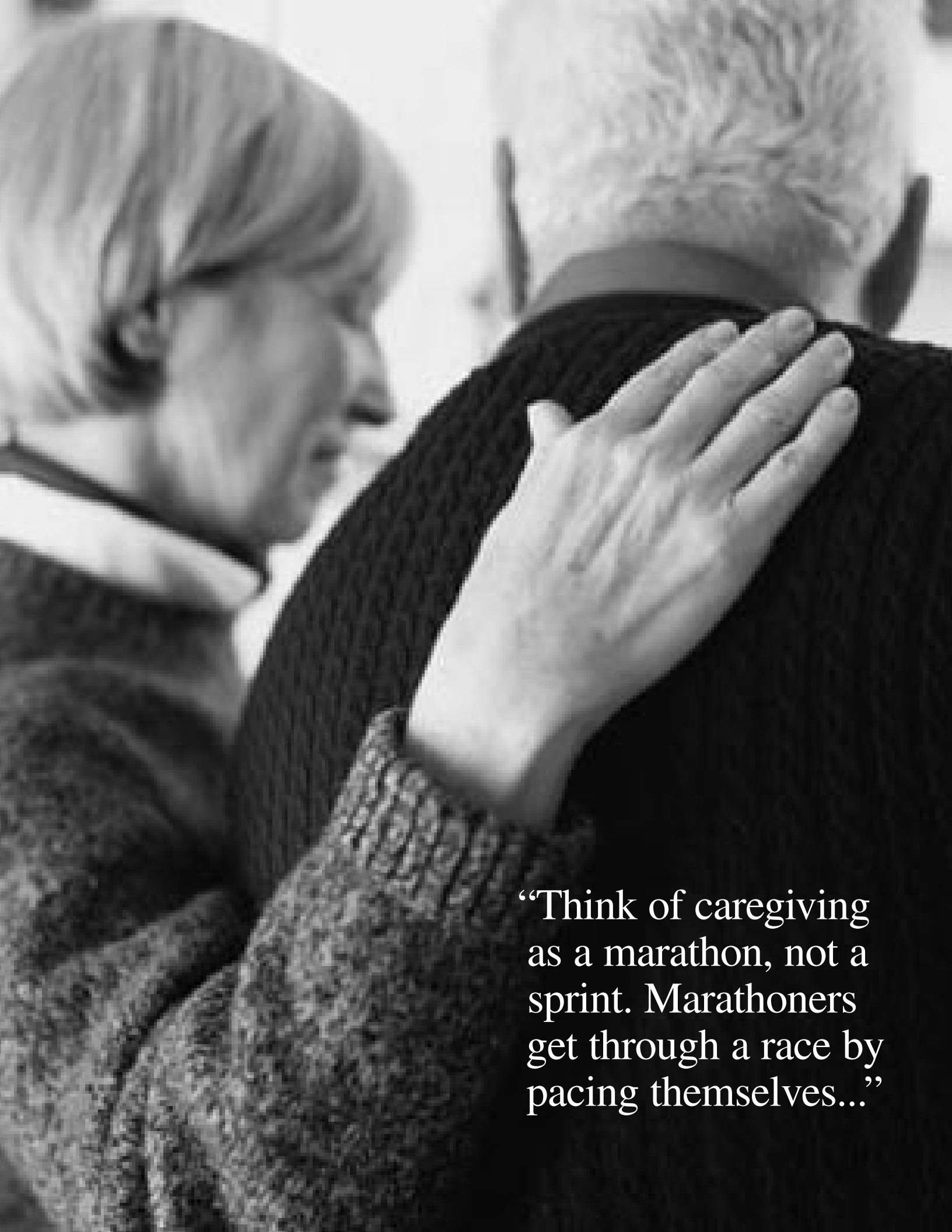
Whether a caregiver comes to this role because of love or guilt or lack of an affordable alternative, the impact of caregiving on caregivers is real and progressive. "Caregivers sacrifice so much of themselves," says Dr. Barry Jacobs, the Director of Behavioral Science at the Crozer-Keystone Family Practice Residency Program. "They experience a real decrease in the quality of their emotional and physical health. They have high rates of depression and suffer significant social isolation."

Researchers have found that caregivers have increased risk of congestive heart disease. Caregivers report increased tiredness and back injuries, and muscular strains are common. Those in the sandwich generation may become chronically sleep deprived as they try to deal with a debilitated parent while still working full time and trying to raise children. It is important to remember that the effects of sleep deprivation, and many other types of stress, are cumulative—that means they keep building up even if they are denied.

Beyond the physical strain, mental stress accompanies caregiving. Taking responsibility for another person carries with it multiple opportunities for guilt, anger, self-doubt and victimization. Caregivers score high on depression surveys, and the depression is often progressive, intensifying if the patient's condition deteriorates or there is little improvement. "Most caregivers can do it for a year or two," says Dr. Jacobs, "but if they go longer than that without significant help, they wear down."

For caregivers who feel thrust into the role, anger becomes an issue that not only affects the relationship, over time it has an impact on the caregiver's well-being. If the patient doesn't improve, disappointment grows as responsibilities mount and energy wanes. There are inevitable psychological costs.

"Depression is sometimes repression," says Dr. Judith Bernardi, LCSW, Ph.D. "People work hard to keep their angry thoughts at bay. Anger is common in this situation, anger at what happened or with the loved one, but it's difficult to express to the patient. It's not socially acceptable to show resentment, so that anger gets turned inward, and caregivers become depressed. Then they don't have energy to deal with things."



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“Sometimes depression is functional, it’s like a time-out, the caregiver is saying, ‘I can’t deal with this anymore,’” says Dr. Bernardi, who is a licensed social worker and medical psychologist in private practice.

It is almost inevitable that family caregiving produces these physical and psychological results. After all, a caregiver’s life is suddenly circumscribed by someone else’s problem, and all of the emotions — why me, this isn’t fair, I’m not up to it, why now — that engenders. And that tumult of emotions will be made worse by the dynamics of the relationship that existed before the stroke.

“The history of a relationship is a good predictor of the impact of caregiving,” says Dr. Bernardi. “If it was a good, strong relationship, where there’s not too much guilt, you don’t see people overdoing out of a sense of not having done enough to prevent this situation. People who feel responsible, or those who feel ambivalent, are often the ones who go overboard in caregiving, to mask their real feelings.”

Caregivers often focus on the worst possible outcomes and stay constantly worried because of that. Mobility issues are common. Some caregivers feel constrained by a societal notion that good people put others before themselves. Too often these factors converge and result in caregivers who never take a break and refuse to ask for help.

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“‘Get help’ is always the first advice we give caregivers, but asking for help is a complex issue,” says Dr. Bernardi. “People fear being turned down, or they don’t want to feel obligated. Some people see it as weakness. For many caregivers who are in a long-term situation, there is a sense that asking for help is an admission that they can’t keep doing this, and what will happen then?”

“There’s also a cultural component to asking for help. In many communities, the family takes care of its own, and it’s not OK to use community or government resources.”

When the task is so complex with built-in stress, guilt and self-doubt, it can be difficult for caregivers to manage the impact. But there are definitely things that can be done to lessen the impact of caregiving and improve the lives of both people. Sometimes big changes can be accomplished by simply changing an attitude, like deciding that people want to help when they offer, not put you in debt.

Another attitude adjustment can change how you spend your energy. “Think of caregiving as a marathon, not a sprint,” says Dr. Jacobs. “Marathoners get through a race by pacing themselves and getting sustenance and water along the way. A lot of people throw themselves into caregiving in a frenzy, but you can’t take a long course and do it at a sprinter’s pace.”

The first casualty for caregivers is personal time and concern about their own health and well-being, so the first law of successful caregiving is “don’t neglect yourself.” It’s the same reason that airlines instruct parents to put on their oxygen masks first, before helping their children. Many caregivers, especially older spouses, come into their role with health challenges of their own, and if they become incapacitated, their survivors cannot suddenly grow the capacity to take care of themselves.

“You can’t see the future,” says Dr. Jacobs. “Caregivers often don’t take into account that this may go on for years, and they need to pace themselves.” A caregiver’s health is of paramount importance. Listen to your body... and respond. Get checked regularly. In addition, it is essential that you know your family history of disease so you can reduce your modifiable risk factors. Don’t deprive yourself of necessities, which include sleep, exercise, proper medication and some personal quiet time.



Because depression is common in this situation, caregivers need to watch for it in themselves and in their survivors. “Many caregivers aren’t aware that they are depressed,” says Dr. Jacobs. “They don’t recognize the symptoms — irritability, not sleeping well, lack of patience — so they don’t get treatment.” Untreated depression complicates everything. In the survivor it jeopardizes any further recovery, while in the caregiver it raises the risk of coronary heart disease.

To fortify yourself emotionally, it is important to find or develop sources of emotional support. A key source is a support group, counselor or clergy person. Caregivers need to share their feelings with someone, perhaps another caregiver in Mended Hearts. Many cities have caregiver-specific groups where those caring for people with a variety of ailments can get together. They can discuss their concerns more openly because everybody in the group has been there and done that. For information on caregiver groups in your area, contact the Well-Spouse Foundation or your local Area Agency on Aging.

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## Getting assistance improves the well-being of both survivor and caregiver.

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When money is a problem, many mental health providers offer a sliding scale for services. Clergy can also be a valuable resource.

Staying connected to extended family and your community helps ease feelings of isolation. “Your social life changes,” says Dr. Bernardi. “People stay away. You can’t get out. It can be like being widowed. I suggest if people can’t get out, then try to do social things by having people come in so you aren’t totally cut off.”

Membership in a church or local group such as AARP can provide a feeling of connection to a larger community, as well as access to other services.

Many caregivers fail to investigate respite care opportunities because of feelings of guilt or fear, but respite care is a vital source of regeneration for overtaxed family caregivers. “There are many caregivers who feel it is their duty to take care of their loved one and resist all family and community efforts to help them,” says Dr. Jacobs. “Some patients tell their caregivers that they don’t want anyone coming to the house, that they want the spouse to do it all. Either of these beliefs will cause problems over time.”

Respite care, where the patient’s care is handled by someone else for a few hours, is among the most important tools in every caregiver’s tool chest of self-care. Unfortunately, it is not uniformly available throughout the United States. For information on respite care in your area, call your Area Agency on Aging.

Few people take on the caregiver role with no reservations, whether about time, resources or their own capacity to meet the demands. Generally caregivers assume their responsibilities out of love and commitment. Others may feel the role is thrust upon them. However a person comes to being a caregiver, it is important to take ownership and admit the possibility that it may be long-term.

Ownership begins with admitting that you are a caregiver, recognizing that this role is vital for your loved one and distinct from other roles in life. You may come to it by free choice, family pressure or societal expectation, but it is a new role with new, different and sometimes difficult requirements. Acknowledging this lets you plan and become proactive in getting help. Getting assistance, whether from family, members of the community or government or nonprofit agencies, improves the well-being of both survivor and caregiver. This job is simply too big for one person, so relying on others is crucial.

A survey by the National Family Caregivers Alliance found that acknowledging that caregiving is a distinct role, a simple shift in attitude, had a profound impact on the caregiving situation. As long as caregivers diminish their roles by saying it is simply what anyone would do when family members need help, they are setting themselves up for stress and emotions that prevent them from seeking help.

Every person has a physical and psychological limit to the stress they can handle. Once that limit is breached, things begin to happen: they get ill or make a mistake in the checkbook or grow impatient or lose sleep or spiral into depression. No one can compromise the necessities — sleep, exercise, medical care and some personal time — for very long without experiencing problems of their own. Long-term caregiving has long-term effects, and the best way to lessen them is to decide from the beginning that this job is too big for one person and to ask for and accept help from as many sources as you can find. “Caregivers resist pacing themselves and finding the help they need,” says Dr. Jacobs. “When they finally come to understand the importance of those things, they may be too burned out. The earlier they come to understand pacing and asking for help, the better they will do over time.”

Caregivers have a tough role, with equal parts stress, frustration, exhaustion and deep emotional connection. That’s why those who take on this job have big hearts, filled with love and compassion. ❤️