



FINDING YOUR WAY

WEB SITES

The Family Caregiver Alliance provides resources, including information about specific diseases and related public policy news. www.Caregiver.org

CaringRoad, an interactive site offering support and information for caregivers, including chat rooms, links and a disease directory. www.caringroad.com

The National Alliance for Caregiving provides information from pertinent studies, tips for caregivers and a searchable resources directory. www.Caregiving.org

New York Beth Israel Medical Center has created the Caregiver Resource Directory to help family caregivers feel less alone and overwhelmed. www.stoppain.org

The National Family Caregivers Association offers practical information and FAQs, as well as "A Guide to Improving Doctor/Caregiver Communication." www.nfcares.org

The American Pain Foundation provides a survey to screen yourself for depression and access to online support. www.painfoundation.org

Partnership for Caring, a consumer advocacy group, offers state-specific, advance directive documents to print or order. You'll also find Talking About Your Choices, a booklet that introduces issues surrounding end-of-life decision-making. www.partnershipforcaring.org

The Midwest Bioethics Center makes available Caring Conversations (www.midbio.org/workbook.pdf), a workbook to help start conversations, including advance health care planning and advance directive forms. www.midbio.org

AARP offers information and resources on caring for an aging parent and other loved ones. www.aarp.org/indexes/health.html#caregiving

BOOKS

"Dying Well: Peace and Possibilities at the End of Life," by Ira Byock (Putnam, 1998; \$14)

"Share the Care," by Cappy Capossela, Sheila Warnock and Sukie Miller (Simon and Schuster, 1995; \$13)

"Changing Places: A Journey With My Parents Into Their Old Age," by Judy Kramer (Putnam, 2000; \$14)

"Always on Call," by Carol Levine (United Hospital Fund; \$20; available at www.uhfnyc.org)

"The Helper's Journey: Working With People Facing Grief, Loss and Life-Threatening Illness," by Dale Larson (Research Press, 1993; \$19.95)

"Elder Rage or Take My Father ... Please! How to Survive Caring for Aging Parents," by Jacqueline Marcell (Impressive Press, 2001; \$19.95)

"Another Country: Navigating the Emotional Terrain of Our Elders," by Mary Bray Pipher (Penguin/Putnam, 2000; \$13.95)

"Losing Your Parents and Finding Yourself: The Defining Turning Point of Adult Life," by Victoria Secunda (Hyperion, 2000; \$14.95)

For more resources, go online to www.findingourway.net

ABOUT THE AUTHORS



Karen Orloff Kaplan is the president and chief executive officer of Partnership for Caring: America's Voices for the Dying. Kaplan has expertise in health and aging issues and in developing health and social

policy. Kaplan's previous academic positions included posts as Clinical Instructor at Tufts University and the University of Cincinnati School of Medicine.



Dr. Ira Byock is director of The Palliative Care Service in Missoula, Mont., director of the Robert Wood Johnson Foundation national program, Promoting Excellence in End-of-Life Care, and is a research professor in the philosophy department at the University of Montana. He is the co-founder and principal investigator for the Missoula Demonstration Project Inc. Byock is the author of "Dying Well: The Prospect for Growth at the End of Life" and co-author of "A Few Months to Live."

Living on the edge

Baby boomers face caregiving dilemma

BY KAREN ORLOFF KAPLAN AND IRA BYOCK

Beth Liebich can't pinpoint the day she officially became a caregiver. Maybe it began in 1995 with her mother's intestinal inflammation. There were the twice-monthly doctor visits and extra trips to the pharmacy and the nearly hour commute across town — from her home in Clifton Park, N.Y., to Saratoga Springs and back — to check on Mom during the week. Things heated up when her father and father-in-law each had cardiac valve replacement surgery in Boston within two weeks of one another.

By 1998 she thought nothing of dropping off her mother at the cardiologist's office, then swinging by to pick up her father-in-law for his ophthalmology or cardiology appointment, making it back in time to hear what Mom's heart doctor had to say.

In 2000, both her mother and father died. So did her husband's father. Now her mother-in-law is in the late stages of Alzheimer's and Parkinson's diseases.

There is no job description for caregivers, but the 25 million Americans who provide care for elderly or critically ill family members do anything from shopping for groceries and medicines to bathing, dressing, feeding, cleaning house, and taking care of the family finances. Often they do it all.

As the population of older citizens grows dramatically — by the year 2030 there will be 5.3 million aging Baby Boomers needing long-term care — many caregivers put their own lives on hold to meet the needs of ill loved ones.

Like Liebich, three-quarters of family caregivers are women. According to the National Alliance of Caregivers and AARP, the average caregiver is a married woman in her mid-40s, a high-school graduate who works full time and earns about \$35,000 a year. But caregivers can be young, old, male, female, employed or out of work, members of large families and small, of every race, faith and denomination. They're caring for ailing parents, husbands or wives, and even children.

And, according to Carol Levine, an advocate for family caregivers, most "go it alone." Nearly 83 percent have no paid professional help, such as nurses, physical therapists or social workers, and nearly 85 percent have no other paid assistance, such as home health aides.

Shirley Loflin, 66, knows what it means to go it alone. When her 83-year-old mother died in 1993 after a long illness, Loflin was left to care for both her ailing father and her husband, Geddie, who suffered a debilitating stroke.

"Geddie was close to retirement," Loflin said. "We were

Caring for an ailing loved one can take its toll, but there is help. Here are some practical tips from www.caregiving.com.

Get things in order. Find financial information, including investments, bank accounts and tax returns, and names of lawyers, bankers and accountants. Locate life insurance policies, birth certificates and funeral arrangements papers. Have the names and phone numbers of all physicians as well as information about all prescribed medications at your fingertips. Find Social Security and Medicare cards. Help your charge complete living wills and durable powers of attorney for health care.

Ask questions. Speak with the doctor about diagnosis and prognosis. Ask what you can expect in the future. Spend time in the library and/or on the Internet conducting your own research. Contact local agencies to get more information.

Get informed. Ask your home health aides or visiting nurses to show you prop-

within touching distance from our dreams of traveling, playing with grandchildren, and finally having time just for one another. Life was full and beautiful until the week before Christmas, when it literally exploded.

"First, Mother died, leaving Daddy alone and bewildered. He couldn't stay by himself, so of course we brought him to live with us. We'd barely settled down to the routine of life together when Geddie, my sweet husband, had a massive stroke, which left him speechless and totally paralyzed on the right side. Within minutes he was reduced to a complete invalid and all our lives changed forever."

Aside from her frantic caregiving duties, Loflin had to deal with daily life and natural disasters in her home in Americus, Ga.

"One week, our old furnace died, the plumbing backed up, the city was in the midst of a huge flood, a small tornado whirled through our neighborhood and ripped off shingles and tree limbs. Debris was everywhere. Geddie had his first seizure and, on top of it all, Daddy was upset because Geddie needed so much of my time."

She got through it all, including the death of her father last October, but the experience shook her. "What scares me most is that you never know what will happen next. Life is from minute to minute. It's living on the edge."

Loflin and Liebich are among the 25 percent of caregivers in the United States who tend to more than one

Practical tips

er hands-on techniques, such as transferring safely, proper skin care and lifting properly. Or contact your local American Red Cross to find a caregiving class. Log your care recipient's health in a diary, and include notes about meals, techniques that worked, medication dosages and any changes in medical condition. This journal will be helpful during doctor appointments and to update family members.

Talk it over. Make sure all family members have the same information you do. Find out what family members can do to help, even if they're out of state. Develop a plan of care. For instance, who will help Mom with her groceries? Who will help her bathe and dress in the morning? Who will take her to her doctors' appointments?

Make time for yourself. This is vital. Pursue your own interests and hobbies. Attend a support group regularly or find an outlet to vent your frustrations,

whether it's friends, family or a daily journal.

Set limits. Determine at what point you no longer can provide care. For instance, some caregivers decide they are uncomfortable when a care recipient becomes incontinent.

Remember why you're here. Although your loved one may act "childish" or may be unable to fully care for herself, always respect her need for independence and choices. Encourage her to do as much as possible for herself — you'll both benefit.

Look ahead. Seek out options for the day when you no longer can provide care. Visit several retirement centers, assisted living facilities and nursing homes to find one that you are comfortable with.

Share, share, share. The best resource for family caregivers is other family caregivers.

— Karen Kaplan and Ira Byock

relative at a time. Even more common is the "sandwich generation," the baby boomers who are tending to their parents while still raising their children.

Liebich, 46, falls into that category, too. A one-time manager at a major national insurance company, she embraced the role of full-time wife and mother in 1993. She always assumed that when her son left for college, she would re-enter the work force. The day her mother and father-in-law both ended up in different emergency departments, she realized her career would stay on the shelf a bit longer.

But her management skills were put to good use in her new role. In the car between stops she'd call the pharmacy to check on the latest prescription and check in with her son as he returned home from high school. She started carrying a Palm Pilot to organize her parents' appointments and medications, necessary, she said, because "otherwise the doctors have no idea what each is prescribing."

Despite her savvy, Liebich's family got caught in a bewildering health-care maze, discovering that insurance or Medicare regulations frequently seemed to be at cross-purposes with quality of care.

One day, while her father was being cared for at home, a private aide took her father to the mall so he could go for a "walk" — he could only shuffle a few feet without stopping to catch his breath. A nurse happened by the house while they were gone. The brief walk meant he was not strictly homebound and now ineligible for Medicare home health aides. The twice-weekly, half-hour home visits by the nurse became twice-weekly, two-hour trips to the doctor for Beth and her father.

Caregiving at this level can take a physical toll. While hurrying to get her father situated in his new assisted-living apartment, Liebich broke her back carrying a heavy carton. After a week in bed, she underwent six months of physical therapy and still maintains a stringent strength-training program. Another time, Liebich had an attack of chest pains and it took a night in the hospital and several tests to assure everyone

that it was strained muscles and frayed nerves.

The cost to the health care system of illness and injury among caregivers is significant. A 1997 study by the National Alliance for Caregiving and AARP found that 15 percent of all caregivers and 31 percent of those providing the highest levels of care experienced significant physical and emotional stress.

The financial picture isn't any brighter. Many Americans simply die poor, with the health care system having absorbed all the money they and their families have.

According to public opinion researchers Lake Snell Perry, caring for an elderly relative ranks as one of the top financial worries for the 21st century, and with good reason. With nursing homes costing over \$3,000 per month, it doesn't take long for most Americans to "spend down" to meet Medicaid criteria for being officially indigent. In a 1999 study funded by the Robert Wood Johnson Foundation of patients with advanced, incurable chronic illness, 29 percent of families reported losing most — or all — of their livelihood and 31 percent lost most or all of the family's life savings. Social Security and pension benefits overall, and out-of-pocket expenses for the care of a single ill relative averaged over \$19,000.

Asked to estimate the amount she and her husband spent in caring for their four parents over the past four years, Liebich quickly ran through the list: There were non-prescription medications, wound dressings and Attends (adult diapers), special foods, occasional "Medi-van" transportation to and from the hospital, minor renovations — handrails in the cellar and halls, elevated toilets, commodes — and, toward the end, nursing aides from the private duty service. Liebich estimated she spent \$75,000 to \$100,000, maybe more. "Thank God, we had the means to do it," she said. "I don't know what other people do."

After her parents died, Liebich faced sorting through their estate — "the caregiver usually gets that chore, too" — but barely had time to face her grief.

"The time to grieve was virtually instantaneous," she said. "When your mother dies on Saturday, your father-in-law on the very next Monday and your father 2½ months later, your day-to-day workload gets cut by three-quarters, but the grief is always with you."

It was probably inevitable that Liebich would become an activist for the plight of caregivers. She has begun writing and speaking out on the issue, intent on educating policy-makers, including legislators and the private foundations that fund innovative health and social projects.

Despite the huge stress, many take on caregiving voluntarily and speak easily about its rewards. They talk about the blessings of giving or the growing self-confidence that comes from mastering one difficult task after another. Still others feel the peace of mind that comes from meeting the needs of someone they love. And some learn more than they thought possible.

"Caregiving has taught me many lessons," said Shirley Loflin, "among them, that it is more blessed to give than receive."

Caregivers are finding more support, ranging from tips to deal with overwhelming amounts of paperwork to respite care that provides them with "time off;" to an array of Web sites containing strategies for coping.

Most important to Loflin is the support provided by people just like her.

"I craved having someone who 'had been there,' had experienced what I was going through," Loflin said. "In the quiet hours of the night, in moments I can catch when my men are asleep or occupied, I'm on the Internet exchanging e-mails with hundreds of other caregivers. We provide huge amounts of support for one another, practical ideas about how to do hard jobs, humor and kindness. These exchanges nourish me and let me nourish others."

For more resources, go online to www.findingourway.net



Beth Liebich provided care for three loved ones during their final years: her late parents, Hugh and Virginia Earley, and her father-in-law, Herbert Liebich.

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