



By Jack Gruber, USA TODAY

Labor of love: Roberta Moore with her mother, Ethel Weinstein, 89, who has Alzheimer's.

Sons, daughters and caregivers

More and more of us are in similar straits: Attending to aging parents

By Janet Kornblum
USA TODAY

SAN FRANCISCO — Every weekday at 6:45 a.m., Roberta Moore quietly pads into the next bedroom and pulls back the curtains to let in the first light. Thus begins the nearly three-hour ritual of readying her 89-year-old mother for her day.

Moore, 57, makes breakfast, brews coffee and ushers her mother, Ethel Weinstein, into the shower. She tidies her room and lays out her clothing and makeup. She puts out only what Weinstein

needs, so she won't get confused, like the day she mistook nail polish for rouge. By 9:30 a.m., Weinstein, neatly dressed, well-coiffed and usually smiling, is driven to senior day care — or what she calls "the club."

Weinstein, who once was a singer and dancer as well as a homemaker, now has Alzheimer's disease. Until May 2002, she lived in her own home 50 miles away in San Jose with someone hired to help her.

But one day "I walked in and, yet



Family photo

From care giving to receiving: Ethel Weinstein as a young mom in the 1940s.

again, the house was dark, the TV was blaring and my mother wasn't dressed," recalls Moore, a former sales manager who now works with her husband in a home business.

She realized that no one could take care of her mother like she could. So Weinstein came to live with them in their San Francisco

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Caregiving by the numbers

Of the USA's 96.6 million households, 22 million (23%) are involved in caring for a relative or friend who is 50 or older. Here's a closer look:

60

percentage of U.S. caregivers who are female

66

percentage married or living with a partner

46

average age of U.S. caregivers

77

average age of care recipients

41

percentage of caregivers who have children under 18 living at home

52

percentage of caregivers who are employed full time

\$221

caregivers' out-of-pocket monthly expenses

\$35,000

median family income of a caregiver household

Source: National Alliance for Caregiving

Cover story



Caregivers must care for themselves, 4D

About a fourth of U.S. households care for an aging relative

Continued from 1D

apartment.

Devotion, dedication, frustration — caregivers provide a selfless kind of love. “Everything has to do with helping their loved one,” says Gary Barg, editor in chief of *Today’s Caregiver* magazine, based in Hollywood, Fla.

Moore, born in the first year of the baby boom, 1946, was never one to map out her future, so she can’t say she had other plans for middle age. But she never imagined — “not in a million years” — that she would be a full-time caregiver for her mother.

Few do.

More Americans than ever are finding themselves in similar straits: suddenly confronted with aging relatives who can no longer care for themselves, and becoming full-time caregivers, often with no

preparation.

“It’s an issue that’s talked about at dinner tables and supermarkets,” says Lynn Friss Feinberg, deputy director of the National Center on Caregiving at Family Caregiver Alliance, a San Francisco-based non-profit that helps caregivers find services throughout the country. “It affects everyone.”

Cover story

And as baby boomers near retirement age, many more will experience it firsthand. “We are entering a tidal wave of the need for caregiving,” Feinberg says. “It’s huge.”

Almost a quarter of U.S. households — 22 million — already are involved in caring for a relative or friend who is 50 or older, according to the non-profit National Alliance for Caregiving. And the U.S. Census Bureau says that by 2050, the percentage of Americans 65 and over will grow to 21% of the population from the current 12%.

As many as 19 million are expected to need some type of long-term professional care. Many adult children, especially those without the financial resources to afford assisted living, will find themselves in the role of caregiver.

“It’s a myth that people get older and move to nursing homes for care,” Feinberg says. “It’s not what the baby boomers want. It’s not what’s happening currently.”

For Moore and others, caregiving is a full-time, live-in arrangement, and means doing just about

“Sometimes I have the most joyous moments. . . . I know there are things that later I’ll look back and say, ‘I’m glad I was there.’ But other days, there is the feeling of ‘Why am I doing this?’ ”

— Kimberly Cooper, 32, of Broken Arrow, Okla., who is taking care of her grandparents full time

everything, including helping a parent dress and bathe.

For others, it may mean managing care from afar, or moving in-firm parents cross-country to supervise their care in assisted living or a nursing home, or picking up and moving closer to them.

For all, it inevitably means a change in lifestyle.

Kimberly Cooper, 32, of Broken Arrow, Okla., gave up a job she loved as an event planner and moved 30 miles so she could care for her grandparents full time. Her marriage crumbled from the stress, and she learned to live on \$800 a month that she gets from her family.

“I love my grandparents to death, but this is a difficult situation and much harder on me than they can possibly realize,” she says.

Caregiving not only takes time and money, it also takes its toll physically and emotionally.

Many caregivers feel isolated and alone, says Gail Gibson Hunt, executive director of the National Alliance for Caregiving. They often

don’t even think of themselves as caregivers, but think, “You know, I’m doing what any good daughter would do.”

Patrick Janzen, 44, brought his father to live in his Charlottesville, Va., home after Janzen’s mother died and his father was suffering from dementia and depression.

Janzen quit his job and started a home business so he could care for his father full time. The stress wreaked havoc on his system.

“My energy was bad, my mood was bad, my sex drive was gone,” he says.

With the support of his wife, as well as medical intervention, he has been able to regulate his own health. His father’s dementia is getting worse, but Janzen is coping, he says.

While caregivers are in the thick of it, legislation addressing the coming crisis is only in its infancy.

In 2000, Congress established the National Family Caregiver Support Program, in which the government provides funding to each state for caregiver services such as respite care, education and training. But the 2003 budget for the entire country was \$155.2 million, the proverbial “drop in the bucket,” says Hunt. Funding for 2004 is \$159 million. The National Governors Association says that, this year, it will focus on developing programs and legislation to deal with long-term care for aging Americans.

A few states have passed legisla-

tion. In 2002, California led the nation in passage of a paid-family-leave law. Hawaii passed a law in 2003 that allows employees to use sick leave for family leave purposes. Congress has considered various initiatives, such as a bill to provide funding for respite care, a bill to provide tax credits for caregivers and one that would give Social Security credits for people who take time off work to be caregivers.

“We are the caregiving generation,” says Beth Witrogen McLeod, author of the 2000 book *Caregiving: The Spiritual Journey of Love, Loss, and Renewal*. “This is a life passage that no generation has ever gone through en masse.”

Those leading the way say that it’s worth it, despite the work, stress and constantly frustrating moments, such as having to stop everything to search for a missing remote control.

“If I were to speak to how I feel, I would be speaking for a million caregivers,” says Cooper. “I feel tired, sometimes angry, sometimes sad.”

“Sometimes I have the most joyous moments. . . . I know there are things that later I’ll look back and say, ‘I’m glad I was there.’ But other days, there is the feeling of ‘Why am I doing this? Just for love? Am I earning a place in heaven?’ ”

Children who did not always have perfect relationships with parents often are thrust into a situation where they are not quite chil-

dren anymore — but not quite parents, either.

There are responsibilities similar to child-rearing, Moore says, but “it’s not the same at all. With a child, there is the learning and the growing. With this, it’s going the other way. You’re regressing. It’s the opposite of childhood.” And that makes her job that much more challenging — and often heartbreaking.

“I certainly didn’t ever think I’d live with my mother in an extended family situation,” Moore says.

Like a lot of children of her generation, she was always battling with her mother. But love is a funny thing: When Moore learned it was Alzheimer’s, she was devastated at the thought that they would never have another fight.

Now, instead of their arguing, her mother usually smiles and complies with simple directions that one might give to a child, such as telling her it’s time for bed.

“I’m losing my mother in little pieces all the time,” Moore says. “My mother’s fading away.”

But then there are other times — like the day she brought her mother to respite care so she could go to New York for a few days.

Moore was having trouble saying goodbye. But her mother sensed Moore’s nervousness. “She took my hand and said, ‘It’s OK, honey. I’ll be just fine.’ ” Moore recalls. “I left, and I broke down in the parking lot, because she was still my mother, making it OK.”

Corrections & Clarifications

USA TODAY is committed to accuracy. To reach us, contact Reader Editor Brent Jones at 1-800-872-7073 or e-mail editor@usatoday.com.

A photo credit was omitted from an item Feb. 13 in the Destinations & Diversions section about an eBay auction of pillows based on TV shows and movies. Bill Hopkins took the picture of the *Will & Grace*-inspired pillow for *Traditional Home*, which organized the auction.



Photos by Kevin Moloney for USA TODAY

“I just followed my heart”: Larry Atencio, 44, moved to Colorado Springs from Denver to care for his father, Felix, who has diabetes.

Caregivers finding someone to lean on

Growing number of programs provide help for the helpers

By Janet Kornblum
USA TODAY

Larry Atencio knew his father had had diabetes for years. But he was still shocked by what he saw a year and a half ago, when he went home to visit.

“Everything was upside down,” says Atencio, 44. His dad couldn’t get out of bed to go to the bathroom; his mother couldn’t lift him.

“She was on the verge of a nervous breakdown,” Atencio says. “I had a pretty good job in Denver, but . . . my parents needed me, so I just followed my heart.”

That meant moving 70 miles to Colorado Springs and becoming a full-time caregiver.

Atencio’s heart may have told him what he should do, but it certainly didn’t tell him how to do it.

That’s the case for most people who end up caring for an aging parent, spouse, or other relative. They have no training in caregiving and no real idea what to do or what to expect.

But there is help. A growing number of classes, support groups, therapy and respite care options are becoming available for the USA’s growing army of overextended caregivers.

Often, however, taking care of themselves is their last priority.

It shouldn’t be, says Mary Mittelman of the Silberstein Institute for Aging and Dementia at the New York University School of Medicine. She began a study in 1987 of husbands and wives who care for an Alzheimer’s-impaired spouse.

Caregivers who received counseling and support were able to cope better. They also could keep their Alzheimer’s-impaired spouses out of nursing homes a median of 329 days longer than those not getting such services, she found. The study is continuing.

For Atencio, help first came from a telephone hotline called the Eldercare Locator. It is paid for by the U.S. Administration on Aging, part of the Department of Health and Human Services. The phone line supplies people with information on local resources.

Through the hotline, Atencio found a local agency and social worker who “sat me down and put a folder together with all the tools I needed. She was like an angel. It made my job so much easier.”

He got his dad’s medication under control and also organized his father’s papers, including a living will.

Atencio regularly attends caregiver-support groups at the local senior center. “They encourage us to stay healthy and ask family and friends to share the care,” he says.

Betty York of Asheville, N.C., also sought support to



It’s a full-time job: “My parents needed me,” Larry Atencio says. But Atencio needed help, too.

help her deal with being caregiver for her mother, 88, who moved in with York and her husband after a stroke and memory loss.

“There is no life,” she says. “It’s a full-time job.”

She took a class called Powerful Tools for Caregivers, a six-session program that focuses on how caregivers can care for themselves. The curriculum was developed by Legacy Caregiver Services in Portland, Ore., and is now administered through Mather LifeWays’ Institute on Aging in Evanston, Ill.

More than 10,000 caregivers throughout the country have now taken the course, which was first offered three years ago and continues to grow in popularity.

“Too often the caregiver’s health gave out before the person receiving care,” says Vicki Schmall, who has worked with family caregivers for 30 years and co-wrote the book used in the Powerful Tools course.

The class, which emphasizes self-care techniques and communications skills, is no panacea. But for York and others, it can make a difference — especially in the most stressful moments.

“Sometimes I want to tear out all my hair and just run and never stop. Sometimes I want to scream, and other times I say, ‘Well, this is what I need to do.’ And I just calm myself down and get through it,” York says. “I don’t get as upset as I used to all the time. I know how to handle it.”

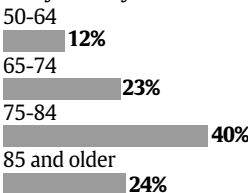
Most important, the class has made her feel less isolated.

It helps to know that “other people feel like I do — they feel tied down,” she says.

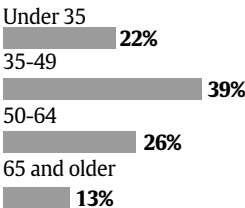
“The bond between the way we all feel is amazing because we have somebody to talk to. You understand? We have somebody to talk to.”

Families and caregiving

Average age of people being cared for by a family member:



Average age of caregivers:



Source: National Alliance for Caregiving

By Robert W. Ahrens, USA TODAY

Where to turn for more information

Eldercare Locator

800-677-1116

www.eldercare.gov

Hotline and Web site, funded by the U.S. Administration on Aging, provide information and locations of Area Agencies on Aging, which refer to local services, support groups and legal assistance.

Family Caregiver Alliance/ National Center on Caregiving

800-445-8106

caregiver.org

Free information on health conditions, care strategies and legal and financial questions.

National Alliance for Caregiving

caregiving.org

Non-profit coalition provides information and resources for family caregivers and professionals.

Alzheimer’s Association

800-272-3900

www.alz.org

Local chapters provide education and support for patients, families.

Faith in Action

877-324-8411

fiavolunteers.org

Volunteer assistance with caregiving, including respite options.

Medicare

800-MEDICARE

Medicare.gov

Online information on coverage, quality of care in Medicare-eligible housing and home health agencies, long-term care alternatives.

National Academy of Elder Law Attorneys

520-881-4005

www.naela.org

Referrals to attorneys who specialize in law relating to aging and caregiving.

National Association of Professional Geriatric Care Managers

520-881-8008

caremanager.org

Links to fee-based geriatric care managers, helpful for long-distance caregivers.

Caregiver.com.

Today’s Caregiver magazine.