

## CONTENTS

# Taking Care of Business

BY LENA HUANG

*How laws help working caregivers.*

As a full-time employee, Mary Barranco didn't know how the next year of her working life would play out when her husband Joe was diagnosed with stage 3 rectal cancer. But as his treatment plan of three surgeries, chemotherapy, and radiation shifted into action, Barranco soon faced the delicate balance of taking care of a loved one, both emotionally and physically, while working full time to stay afloat financially.

“The biggest pressure is that illness knows no time limits,” Barranco says. “It never punches out, doesn't make allowances for the needs of an employer, and certainly doesn't recognize when a caregiver is teetering on the edge.”

Barranco's experience is not unique. With more than 1.4 million new cases of cancer estimated to be diagnosed this year, at least an equal number of friends or family members will be introduced to caregiving, and many of those caregivers also work full time or part time. As caregiving impacts so many people and the businesses they work for, government legislation and programs have emerged to protect and help employed caregivers.

In “Caregiving in the United States,” a 2005 research report by the National Alliance for Caregiving and the American Association of Retired Persons (AARP), researchers estimate more than 44 million Americans, or approximately 21 percent of U.S. households, currently provide care for an adult family member or friend.

The same study reveals that of the more than 1,200 caregivers interviewed, 59 percent were working full time or part time, and 62 percent of these working caregivers felt they had to make adjustments in their work life, such as leaving early or taking time off, in order to meet their caregiver responsibilities.

**National Impact**

The first federal law to help employees balance family responsibilities and work was the Family and Medical Leave Act (FMLA) of 1993. The FMLA guarantees some employees up to 12 weeks of job-protected leave to care for a child, spouse, or parent with a serious health condition. The law specifies that the employee's health benefits will be maintained during the leave, and upon return, the employee will be restored to his or her original job or to a job with equivalent pay and benefits.

“But a very small percentage of people use FMLA for elder care,” says Gail Gibson Hunt, president and CEO of the National Alliance for Caregiving, a nonprofit coalition of national organizations focused on caregiving. “Most people use it for their own sickness or for child care, such as adopting a child. Another reason people don't use it is because it is unpaid.”

Barranco said she didn't take advantage of FMLA because she saw it as a last resort. “I never knew if Joe's condition would worsen, so I kept telling myself I would save FMLA for a time I could no longer handle it,” Barranco says. “That time never came.” Her husband recently completed treatment, and currently, there is no evidence of disease.

FMLA doesn't apply to all employees. Currently it is only binding to companies that employ 50 or more people, leaving out a large portion of the population who work for smaller companies. To address that issue, an amendment to the FMLA was introduced in 2005 to include companies that employ 25 or more people. But that legislation is still pending in Congress, leaving a gap for workers of smaller companies.

Other amendments have been introduced to expand the FMLA. Two versions of the Family Leave Insurance Act (FLIA) were recently introduced—last year's Senate bill was followed by this year's bill in the House. The FLIA bills propose allowing up to eight to 12 weeks of paid leave for employees taking time off under the FMLA. This benefit would be financed by employee and employer premiums that are pooled under a “Family and Medical Leave Trust Fund.” The legislation is pending.



Mary Barranco cared for her husband while continuing to work full time. Photo by Shauna Bittle

With the FMLA up for change, some states have stepped forward to pass their own family leave laws to support working caregivers.

California was the first state to pass paid family leave legislation in 2004. The law, called the Paid Family Leave Insurance Program, applies to employees who are covered by state disability insurance or similar plans, and replaces approximately 55 percent of an employee's wages up to \$917 per week. It is funded by deductions from employees' paychecks.

Although California's law applies to caregivers of ill loved ones, Hunt notes not all states are following that example. "Many of the states that are considering paid family leave do not mention elder care [in the legislation]. For example, the state of Washington's paid leave program only applies to pregnancy or an adopted child," says Hunt.

Indeed, the state response is mixed. Minnesota introduced a bill this year that only covers time off for newborns or newly adopted children. On the other hand, New Jersey passed a law this April that extends temporary disability insurance benefits to care for sick family members, as well as a new child. This legislation provides six weeks of up to 66 percent of weekly pay that is financed through paycheck deductions.

Other states with pending legislation that covers elder care are Arizona, Massachusetts, New York, and Pennsylvania. Ask your state representative where your state stands with paid medical leave.

"Paid family leave is not exactly a big trend," says Hunt. "We have to fight to see that caring for a sick or elderly relative is included."

## Other Initiatives

About 10 years ago, three states—Arkansas, Florida, and New Jersey—were chosen to participate in a unique empowerment program for Medicaid consumers called "Cash & Counseling."

Sponsored by The Robert Wood Johnson Foundation, the U.S. Department of Health and Human Services (DHHS), and the Centers for Medicare & Medicaid Services, the program provides budgets to Medicaid recipients so they can make personal choices on the direction of those funds, such as paying a friend for caregiving or purchasing goods and supplies. Counselors work with recipients to help them plan and manage their budgets.

"Almost all Cash & Counseling program participants use their budgets to hire caregivers and, on average, 80 percent of their budgets are spent on caregivers," says Pamela Doty, PhD, senior policy analyst for the Division of Disability, Aging and Long-Term Care Policy with DHHS. "A majority have hired family members, although the percentage varies from state to state and by target population. The elderly are especially likely to hire family caregivers."

Doty says the program has been very successful and is currently in 15 states, but "many other states have been inspired to adopt similar 'personal budget' options."

Barranco didn't have these options but says her employer was sympathetic to her needs and flexible with her schedule.

“As a long-time manager of others, I knew my employer needed to know my plan and if I could do my job. I recommend that others explore what their company is willing to do. Meet with your supervisor and human resource team to explore options. Make very well-informed decisions, and take your time about making them,” she advises. And make sure you know your rights, available benefits, and how they apply to your individual situation.