

## For caregivers, health, well-being and finances can suffer

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Madhouse Muse

Steven Hirsch and his wife, Jacqui, who is disabled by secondary progressive multiple sclerosis, spend the morning with their dogs, Abby and Jake, at a dog park in Irvine.

More than 6 million California adults provide care for a family member or friend with a long-term illness or disability. These informal caregivers manage bills and medications, clean and cook, and help their loved ones with tasks they can no longer do themselves – often at the expense of their own health, well-being and financial stability.

California's caregivers have higher levels of psychological distress and engage in more poor health-related behaviors than do their non-caregiving counterparts, according to a [study](#) released last week by the UCLA Center for Health Policy Research.

Nearly 52 percent work full time in addition to providing an average of more than 21 hours of care each week.

Few are compensated for their care; one in five spends more than \$250 of their own money on caregiving each month.

Just over 42 percent of caregivers are ages 45 to 64. They often are among the "sandwich generation" – people struggling to meet the needs of their growing children and aging parents. Analyzing data from the 2009 [California Health Interview Survey](#), researchers found many middle-aged caregivers had health problems such as high blood pressure, diabetes and heart disease. Compared with their non-caregiving counterparts, they were 25 percent more likely to binge drink, 16 percent more likely to smoke and 30 percent more likely to be obese.

"Middle-aged caregivers were essentially setting themselves up to be the next generation of care recipients," said Geoffrey Hoffman, lead author of the study and a doctoral candidate at UCLA's School of Public Health. "They care for others but, unfortunately, don't care for themselves."

California Watch reached out to caregivers in the state using the [Public Insight Network](#), an engagement platform that connects journalists with people who want to share their knowledge and insights. Caregivers spoke not only of challenges in navigating health systems, juggling work and children, and making ends meet, but also of the joy they gain from supporting their spouse, parent, child or friend.

"Nobody felt like they were getting a fair deal," said Tim Goncharoff, who helps his wife with tasks such as medication, bathing and pain management.

The Santa Cruz couple had two young children when she became disabled about 10 years ago. "Meeting their needs as well as hers, while still trying to earn a living and take care of the house, has been tough," he said. "I have little time for myself and sometimes struggle with hopelessness."

In the survey, respondents were asked a series of questions to assess psychological distress. Nearly 14 percent of caregivers reported symptoms of moderate psychological distress, and 4.3 percent had symptoms of serious psychological distress – a condition that could signal the need for mental health care, Hoffman said.

Among caregivers with moderate or serious psychological distress, 76 percent said emotional distress interfered with household chores. Eighty percent said emotional distress interfered with their social lives.

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Financially, things have been tough for Steven Hirsch and his wife, Jacqui, who is disabled by secondary progressive multiple sclerosis.

In 2005, she began having trouble climbing the stairs of their two-story condo in Irvine. Because a stair-glide system could not work with their stairwell, they spent most of their savings to fix their home and put it on the market. They found a one-story home nearby and were confident a buyer would come along for their condo, even though the first had backed out.

"What a mistake," Steven Hirsch said. No second offer ever came, and the couple was stuck with two mortgages amid the real estate downturn. They rented the condo at a loss for five years before completing a short sale last month.

Aside from Jacqui Hirsch's Social Security, disability and Medicare benefits, the couple has received little financial assistance for care. Steven Hirsch used to receive \$300 a month for caregiver relief through a local caregiver resource center before its funding dried up. Other state services are out of reach.

"It's a catch-22," Steven Hirsch said. "I earn too much to qualify but not enough to afford."

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Even as a nurse, Richelle Koeppel said she felt overwhelmed by managing care for her mother, who died from cancer in July.

"What caregivers need is someone else to fight the insurance battles ... so that we can spend quality time with our family member, or even just rest," she said.

Only 7.4 percent of caregivers are paid for their help, and only 13.5 percent have ever used respite care, according to the study.

"There needs to be support for the supporters," Hoffman said. "The supportive services that California should have and has had in the past ... are being diminished, and that is making the task of caregivers more difficult."

The state's Adult Day Health Care program, which serves about 35,000 people each month in 330 centers across the state, is scheduled for elimination Dec. 1. Millions of dollars have been cut from the state's In-Home Supportive Services program, and an additional \$110 million in "trigger cuts" could take effect Jan. 1 if revenues fall short.

Ken Etchebarren used to receive \$7.50 an hour through In-Home Supportive Services to care for his wife, Susan Dale. He no longer qualifies for the program since inheriting his parents' trust funds and now looks after Dale, who suffers from chronic fatigue syndrome, full time.

"It used to make me all upset and angry and defensive, and I was a mess," said Etchebarren, noting that he didn't adapt to being a "housewife" or caretaker easily. He said the role has helped him learn what's really important in life.

"It matters to have enough money to live without a struggle, and it matters to love each other like crazy," he said. "And that's what I get out of it. I get a lot of love from an adorable, loving woman."