

from the front page

A DAILY SUN SPECIAL REPORT



5 Facts About U.S. Caregivers

Rewarding and draining.

1

There are 40.4 million unpaid caregivers of adults ages 65 and older in the U.S. Nine in 10 of that group are providing care for an aging relative and others are caring for a parent, according to the Bureau of Labor Statistics.

2

Roughly one quarter of people ages 45 to 64 care for an older adult. Adults 65 and older are the second age group most likely to become caregivers, many caring for partners, a friend or neighbor

3

Most caregivers for aging parents are likely to help in the form of running errands and doing house-work rather than financial or personal care. Women are twice as likely as men to provide personal care such as bathing.

4

A big role of caregiving is emotional support, 68 percent of adults say they offer emotional support sometimes. 39 percent of women say they provide emotional support while 30 percent of men say they do.

5

Most adult caregivers say the task of helping an aging parent who is 65 or older is rewarding rather than stressful. All are generally comfortable with the level of care they provide for their parents or relatives.



Jack and Sharol Lewin, of the Village of Bonita, sip their coffee while sitting with their dog, Sami, outside Starbucks Oct. 26 at Lake Sumter Landing.

Max Gersh | Daily Sun

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issue of training. Eighty-seven percent of caregivers learned how to provide long-term care “on the job” or by teaching themselves, an AP survey of caregivers found.

“Nobody gives you training, and the doctors are overwhelmed with everything that they have to do,” Rinkoski said.

To combat this, Elder Options offers Savvy Care-giver training quarterly in

The Villages. The Alzheimer’s Association also holds its Care-giver College program here throughout the year.

Becoming A Caregiver

Jack met Sharol 42 years ago. Both were long divorced from their first spouses when he asked her out on their first date.

“I said, ‘But I have four kids.’ He said, ‘Well, I’m only asking you to go to dinner.’” Sharol recalled.

A year later, they married.

In addition to working, the Lewins volunteered to run the Miss Miami scholarship pageant for 25 years.

Nine years ago, they moved to the Village of Bonita. Jack went first so Sharol could work a little longer at her job.

“He came up here, moved everything in like a good guy,” she said. “He was so vibrant and knowledgeable, constantly working on crossword puzzles, constantly doing something.”



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About four years ago, Jack started noticing some changes in himself. He was diagnosed with white matter disease, thought to be caused by small, silent strokes that cause degeneration of the brain’s white matter. Realizing what he could lose, Jack wrote down memories sorted by ages and handed them to his wife. Sharol said she didn’t think anything of it at the time. She didn’t look at the paper until about a year ago, finding scattered remembrances: Jack receiving his first bike; the death of his first dog, Buttons, when he enlisted in the Air Force. Jack was always a good dancer, Sharol said. Winning a dance contest as a teenager — the twist — is listed among the accomplishments he passed on to his wife. When they moved to The Villages, the Lewins danced at the square every night. As Jack declined, his love of music held strong. Sharol, however, no longer could bear

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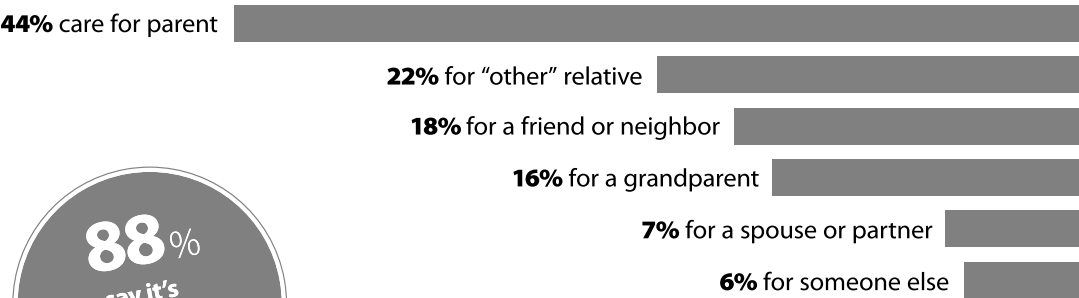
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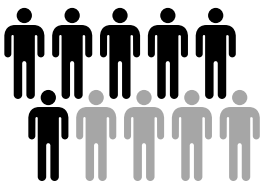
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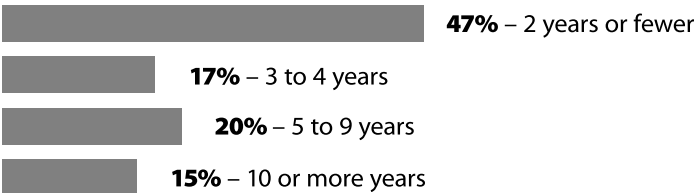
Villagers who care for a spouse are anomalies on the national level, where, of total caregivers surveyed in a Pew study ...



88% say it's rewarding to care for an aging parent.



Roughly 6 in 10 caregivers say they help at least one parent 65 or older with errands, housework or home repairs.



Source: Pew Internet Health Tracking Survey, Aug. 7-Sept. 6, 2012. Margin of error is ± 2 percentage points.

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to take him.

Others don't know Jack the way she did — a graceful dancer, a man who could hold a conversation about anything.

"People here don't know that," she said. "Even our close friends say, 'He never was much of a talker. But I knew him as a talker.'"

Sharol was afraid Jack, "a man who did everything," would be embarrassed by his need for help with daily tasks. He has never complained, she said, aware he doesn't have a choice.

"He can't do it anymore," Sharol said.

A proud Air Force veteran, Jack never knew what it was like for a stranger to stop and ask him about his service until he moved here. Now he doesn't know the answers.

"It's a big change and hard to accept at times," Sharol said.

She stays occupied while sitting with Jack by working on gifts for her family. Two years ago, she made "smile jars" containing positive messages.

The idea was picked up by her family in an ongoing Facebook Messenger chat.

"She's trying to outdo herself every year at Christmas," Windgett said. "She's the most amazing, creative, loving woman I've ever met."

Her daughter said she wishes more people knew her mom's story. Sharol got married as a teenager,

dropping out of high school.

She went on to raise four children, start her own business, go back to school, get her degree and then spend decades doing the work she loved — helping refugees find employment.

"She accomplished an awful lot, and I don't think in my lifetime I'd be able to accomplish as much," Windgett said.

Knowing her mother's strength, Windgett is glad Sharol has taken small steps to accept help from the community.

Finding A Way With Local Support

More than 20 caregiver support groups meet in the tri-county area.

Some run simultaneous respite care and support groups, such as the Alzheimer's caregiver group meeting Thursdays at New Covenant United Methodist Church.

Taylor and Rinkoski agreed that support groups are instrumental for helping caregivers to cope.

"The main thing to remember is that caregivers are not alone. There are so many people who are having shared experiences," Taylor said.

Other caregivers understand the challenges in a way that others cannot, she added.

"It is work, and it's still a source of work that goes unrecognized in society," Taylor said. "But it's still very, very

important work."

Pauline Kimball, of the Village of Liberty Park, understands the struggle. She has cared for her husband, Ken, since his diagnosis of Lewy body dementia.

"Every day is a challenge," she said, her voice breaking. "It is a challenge."

Like Sharol, Pauline said she is doing the best she can, considering the circumstances.

"I tell people I just put one foot in front of the other and I get up in the morning and I just go," she said.

Though Ken can still converse, his body is withering. He takes slow steps with his walker after rising from his chair with Pauline's help, her left hand in his, the right under his armpit.

Because of his frailty, Pauline said, many friends have taken a step back.

"People avoid a person who's not well," she said. "I can't blame them."

Pauline has moments when the weight of it all hits her, like when she received a phone call recently.

"I said, 'I can't talk right now. I think I'm going to cry,'" she said. "That's how tired I was."

The hardest part for Ken? "Losing your freedom," he said.

Still, both are surprised by the kindness of strangers. A waiter at a local restaurant once asked Ken if he needed help cutting up the meat he had ordered.

CAREGIVER HELP

To find out if you qualify for state caregiver programs, call the Elder Options Helpline at 1-800-963-5337.

When Ken was halfway through his meal, the server circled back and cut the rest. "You can't forget that," Pauline said.

Pauline and Sharol praised the support they have received from their neighbors, not one of whom expects anything in return.

A small army of volunteers, churches and clubs step up weekly to give caregivers a break.

Earlier this year, Sharol started dropping Jack off at the My Time for Free Time respite care group at Hope Lutheran Church.

She was reluctant to do so because she feared Jack wouldn't enjoy it. She was pleasantly surprised.

"You don't realize how much they will do without you," Sharol said. "You think you can do it all."

Windgett said though she wishes her mom would accept more help, she understands why she is determined to care for Jack.

"Caregiving is an act of love. You do it because you love them," she said. "Whether they know it or not, you're giving

them a piece of yourself when you're caring for them."

Despite the physical and mental strain, 56 percent of caregivers said their work has a net positive impact on their lives.

The My Time meetings have become a bright spot for the Lewins.

Sharol shows up 20 minutes before the meeting's end, as the musical entertainment is still happening.

"The minute he sees me walk in the door, he comes over and wants to dance," she said.

Though most answers come slowly from Jack now, his favorite thing about his wife is easy — everything.

So, for a few minutes every week, Jack takes his Sharol's

hand. It's no longer out on the square, and his moves are a little clumsier. But together, they dance.

Ciara Varone is a staff writer with The Villages Daily Sun. She can be reached at 352-753-1119, ext. 5395, or ciara.varone@thevillagesmedia.com.

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