



Barbara Cameron, left, who was a caregiver for her mother and mother-in-law, expresses concerns about her husband, Robert, and wants to learn more about Alzheimer's during an educational event in West Valley City earlier this month.

PHOTOS BY FRANCISCO KJOLSETH The Salt Lake Tribune

Middle-aged adults face burnout caring for kids and an aged parent

Caregiving

support

It also found that as people provide more hours of care for a loved one, they're more likely to delay their own health care and experience financial and mental stress — as they struggle to balance caregiving, family life, work and self care.

As Utah's population ages, and more people require care, it's likely more caregivers will need support.

There are several support programs available, from money to pay for adult day care to classes on managing stress.

But, Cole said, there needs to be more long-term support and recognition of the work caregivers do and what they endure.

CAREGIVERS EXPERIENCE DIFFICULTY BALANCING THEIR OWN NEEDS

The policy institute surveyed Utah adults who have offered short-term or long-term assistance to a family member or friend with a serious or chronic illness or disability during the past year.

It found that most caregivers who responded are working at least part-time jobs, and nearly 50% are working full-time.

And though the majority report no concerns with mental health, the likelihood of experiencing moderate mental health issues increases as people provide more care.

So does difficulty balancing their own needs.

For example, 23% of caregivers surveyed reported they had delayed their own health care because of caregiving responsibilities.

That number increased as caregiving hours increased, from 9% of people providing up to five hours of care to:

- 33% of people providing six to 20 hours of care.

- 37% of people providing 21 to 40 hours of care.

- 51% of people providing more than 40 hours of care.

People providing more than full-time care also were more likely to report they often felt they didn't have support and weren't doing enough for their loved ones.

The report acknowledges the survey had limitations, including that some people may screen calls or not have the time to do a 10- to 12-minute phone survey.

The survey, Cole said, may not have captured a "wide spectrum" of caregiving, from helping a parent who lives down the street with chores and groceries to providing 24-hour care for a loved one with dementia.

Joyce Swan and her younger sister are on the lesser end of that spectrum, caring for their older sister, Ruth Swanson.

Swanson can still get through her daily routine and is still in her home.

"She's the toughest out of all of us," Swan said of her older sister.

Swan said it's their goal to keep Swanson in her own home as long as possible before she needs to move in with one of them because she's "quite a nester and a



Donna Cross, a research associate professor at the University of Utah with a doctorate in neuroscience, talks about her research at the Alzheimer's education conference in West Valley City.

homebody."

Swan sees "so many things" that Swanson misses, but said it can be hard to communicate about memory lapses and other common Alzheimer's symptoms because she doesn't want to worry her older sister.

Then there are the sensitive topics that are hard to address, Swan said — such as following up on the doctor's advice to be careful of urinary tract infections. Swan said she wasn't always sure how to ask her sister about that, though Swanson joked that she usually tells her sister everything.

Donna Cross, a research associate professor at the University of Utah with a doctorate in neuroscience, has been closer to the other end of the spectrum. She and her husband took care of his father for four years in their own home before his anxiety and paranoia increased.

"We used to go into his room and find rotted food," she said, and they moved him to a home when it became too much to handle.

Anxiety, paranoia and similar symptoms are what Cross thinks caregivers "have the hardest time with."

Alzheimer's and brain injuries are personal to Cross — besides her father-in-law's dementia, her grandmother had Alzheimer's.

They're also at the crux of her career. She's spent more than a decade shepherding research that's being lauded as a significant breakthrough in treating brain disorders and has shown promising results in mice.

She's trying to raise money to bypass the need to apply for federal funding — a process that could set her research back another year, even as she's sensing there's an urgent need for it. Minutes after she finished giving a speech on her research, a woman approached her asking about human trials because she'd like to get her mother into one.

While people wait for a fix, Cross recommends that caregivers make sure their loved ones are exercising. Research has shown exercise can reduce cognitive decline.

Cameron, who cared for her mother and mother-in-law, added it's important to find resources as soon as possible. She came to the conference to hear Cross' research and learned about several resources she didn't know were available.

SUPPORT GROUPS, EDUCATIONAL PROGRAMS, OTHER SERVICES ARE AVAILABLE

Utahns likely will need more support and resources in the coming decades, as the state's population ages.

In 1980, less than 8% of Utah residents

PHOTO BY FRANCISCO KJOLSETH CAREGIVING, NEXT PAGE

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