

HEALTH

Caregiving Is Hard Enough. Isolation Can Make It Unbearable.

Paula Span

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For years, Marcy Sherman-Lewis went to a beauty salon in St. Joseph, Mo., every few weeks for a haircut and highlights.

It had become something of an ordeal to prepare her husband, Gene Lewis, for this outing; he has Alzheimer's disease, at 79, and helping him shower and dress, insert hearing aids and climb into the car was a very slow process.

But she could no longer leave him at home alone. And once at the salon, "he just sat, watched TV, slept — didn't bother anybody," said Ms. Sherman-Lewis, 62. Her stylist kindly trimmed his hair, too.

Then last month, the salon owner took Ms. Sherman-Lewis aside. "Marcy, he makes my other patrons awfully uncomfortable," she said.

"I was dumbfounded," Ms. Sherman-Lewis said. "It's O.K. for other people's little grandchildren to be running around sometimes. What am I supposed to do, keep him in a crate in the car?"

Like so many caregivers, she has discovered that along with the abandoned career, the hands-on tasks, the medical scheduling, the insurance tussles and the disrupted sleep, she faces another trial: social isolation.

“It’s hurtful,” she said. “You need friends more than ever.”

But where are they? Betsey Brairton, 48, cares for her mother, Sue, in rural Olean, N.Y. The elder Ms. Brairton, 79, suffers from spinal stenosis, arthritis and lingering damage from a stroke, so she has limited mobility. “We hardly go anywhere, and nobody comes here,” said her daughter. When she does leave for an hour or two, she’s afraid to put down her cellphone.

Though a couple of friends occasionally invite her out for dinner, “I can’t commit to anything, in case my mom is having a bad day,” Ms. Brairton said. She has begun to worry that when she does spend time with others, her narrowing life leaves her with nothing interesting to say.

Those who work with caregivers know this phenomenon well, especially when the cared-for person has dementia, a particularly arduous responsibility.

“Caregiving is done with a lot of love and affection, but there’s a lot of loss involved,” said Carey Wexler Sherman, a gerontologist at the University of Michigan Institute for Social Research. “People talk about friends disappearing, about even family members not wanting to be involved. It’s a lonely business.”

Sometimes, caregivers isolate themselves. Barbara Moscovitz, senior geriatric social worker at Massachusetts General Hospital, hears clients lament that with a loved one whose dementia-related behavior can be startling, venturing out in public creates more apprehension than pleasure.

“They say, ‘I’m exhausted trying to explain to people why she’s doing what she’s doing, why they shouldn’t be angry or afraid,’” Ms. Moscovitz said. “It’s just easier to stay home.”

Yet a habit of avoiding others — or watching them avoid you — collides with a growing body of research showing how damaging isolation and loneliness can be. They are associated with a host of ills, including heart disease and stroke. Among older people, isolation is linked to depression, even higher mortality. Lonely old people, Dutch researchers have found, are more apt to develop dementia.

We've long thought of these factors as dangers for the people being cared for. But they also imperil caregivers, who are often older adults as well.

Years of caring for his wife, now deceased, who had early onset Alzheimer's, left Les Sperling, 65, so despondent that "I'd stay in my room in the dark and sleep all day," he said. "I didn't want to come out."

Mr. Sperling, of Lake Worth, Fla., went into therapy and took antidepressants until he felt able to function again.

We know something about how to help caregivers feel less alone. Researchers have shown that even modest-sounding interventions can reduce their sense of isolation and improve their mental and physical health.

Mary Mittelman, director of the Alzheimer's Disease and Related Dementias Family Support Program at NYU Langone Health, has been conducting such studies for years.

With federal and state grants, the program — involving several counseling sessions, followed by support groups and phone access to counselors as needed — has inspired others that have been adopted throughout New York and in several other states.

"The support is what leads to less stress, less depression, better health and delayed nursing-home admissions," Dr. Mittelman said. Interestingly, her team has found that "instrumental support," in which others actually help with tasks, has less impact than emotional support.

"Having someone outside who is paying attention and who cares is more important," she said.

Other initiatives, like Savvy Caregiver and REACH, have demonstrated similar effectiveness. Because they are offered under various names in different states, Area Agencies on Aging can help besieged caregivers find free local programs. And since getting out of the house can be a struggle, program developers are also testing online versions.

Caregivers already gather in Facebook groups and on websites, but experts have mixed feelings about online chats and groups. “They provide anonymity, and that may permit more honesty,” said Dr. Wexler Sherman, the gerontologist. “Sometimes you need to vent at 2 a.m.”

“But we need skills,” she said. “Being a caregiver is a job.” Online, is the information passed along accurate and useful? Is there a trained, knowledgeable moderator?

“It’s important to have a leader to monitor and validate,” said Ms. Moscovitz, who leads several support groups for Mass General employees and for community members. Besides, “there’s nothing like a real person to hug you.”

On other fronts, we’re seeing more efforts to provide convivial social and cultural events for both people with dementia and their caregivers: Memory Cafes, museum programs, choruses. The Dementia Friendly America campaign aims to make whole communities — including police forces, churches, restaurants and hair salons — more knowledgeable and accommodating.

Individuals can also play a role. It’s too easy to let caregiving friends slip off our radar with a general call-if-you-need-anything.

“Don’t put the pressure on the caregiver to tell you what to do,” Ms. Moscovitz said. She suggests asking what would be helpful, making a list of specific tasks and parceling out assignments.

“Don’t invite me for lunch — you know I can’t go,” Ms. Sherman-Lewis said. “Just bring a pizza and a bottle of wine and come by.”

Though tangible help counts — and let’s acknowledge that an aging country can’t rely solely on families, friends and volunteers to provide everything dependent elders need, however well supported they are — so do regular texts, calls or visits. They help keep caregivers from feeling invisible and forgotten.

Counselors in the NYU program once had the friendly inspiration, since they kept caregivers’ information in their database, to send clients a card on their birthdays.

It sounds sweet, if trivial. But often, Dr. Mittelman said, “they’d call up, so grateful, and say, ‘You’re the only one who remembered.’”

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