Caregivers' stress and worries grow as pandemic lingers

The pre-Covid safety net of family, home health and adult day care collapsed, leaving those who tend loved ones more anxious, sometimes resentful, and, often, alone.

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Kay Dungan, left, with Joe Dungan of Fairview, Texas. This photo, taken about three years ago, is Joe's favorite. He was diagnosed with dementia about six years ago. (Photo courtesy of Kay Dungan)

Written By Jan Jarvis

Note: iPondr contributor Jan Jarvis spoke with Kay Dungan and Kimberly Scott, both of whom live in Texas, before the devastation of the recent winter storm. We will try to reach out to them again to check on their welfare.

On Nov. 13, 2020, Joe Dungan stepped out of the shower and told his wife of 27 years that he was going to fall.

She shoved a chair under him before he hit the floor. As his caregiver for six years, Kay Dungan was used to watching out for her husband, who has been diagnosed with dementia.

What she wasn't used to was what came next.

After her husband's fever reached 104 degrees, he was tested for Covid-19. He tested negative, but she was positive for the virus.

A month of isolation, exhaustion, stress and struggle followed as the Dungans quarantined together, with Kay Dungan keeping her distance and family leaving food on the doorstep.

"It was difficult just to feel like taking care of myself, much less someone else," said Kay Dungan, who lives in Fairview, Texas. "But you know, you just do what you have to do."

Her assertion could become an anthem for the estimated 48 million caregivers in the United States, according to <u>AARP</u>. The mammoth task has become more difficult with health restrictions of the Covid-19 pandemic.

"Everything is falling on caregivers now," said Christina Irving, client services director and family consultant for the <u>Family Caregiver Alliance</u> in San Francisco.

The safety net of services that made caregiving more manageable is limited, said Jenna Fink, senior community services manager for the Alzheimer's Association of Minnesota and North Dakota. "Before Covid, they had adult day care centers, home health, neighbors and family members to help them," Fink said. "Now, they don't."

The stressors can lead to anxiety, depression, obesity and a weakened immune system, according to the U.S. Department of Health and Human Services' Office of Women's Health, which is in Washington D.C., and coordinates health efforts across HHS.

Kimberly Scott moved from Houston to El Paso to care for her mother, who has dementia. When 74-year-old Hilda Anderson injured her back, Scott worried about how to care for her. "My mother had a wheelchair, but she couldn't remember she needed it," Scott said. "Every day she'd try to get out of bed, without realizing she couldn't walk."

When Covid-19 hit, anxiety led to a panic attack, then hospitalization for Kimberly Scott. "It was stress beyond stress," she said. "I couldn't sleep or eat. I basically had a nervous breakdown."

For many families, the Covid-19 pandemic has complicated caregiving in ways they never imagined. Fink said that it can be challenging to take care of people who don't understand why they must wear a mask.



In this 2017 photo, Kimberly Scott, left, shares a moment with her mother, Hilda Anderson, and her brother Gene on her mother's 70th birthday in El Paso, Texas. Hilda Anderson has dementia, and Kimberly Scott says the stress of caregiving during the pandemic led to a nervous breakdown. (Photo courtesy of Kimberly Scott)

Scott said it has been a struggle to help her mother understand the coronavirus. "It has been heartbreaking that my mom thinks her friends don't want to hang out anymore," she said. "She thinks she is not loved."

The struggle can stress out the caregiver. It is not unusual for caregivers to feel resentful, guilty and trapped, said Barry Jacobs, a clinical psychologist in Springfield, Pennsylvania.

"But self-criticism, self-doubt and guilt are not helpful," he said. "It's tough enough taking care of someone without being critical of yourself."

The isolation can be difficult. "It is really tough to be with someone all day who asks you the exact same question a million times," said Jacobs, co-author of "AARP Meditations for Caregivers: Practical, Emotional and Spiritual Support for You and Your Family" (Da Capo Lifelong Books, 2016). Dottie Gandy, who leads the <u>Unity of Dallas Caregivers Support Group</u> in Texas, recalls how frustrating it was when her husband, Tom, repeated the same question.

"He'd sit in his recliner and ask me what I was planning for dinner that night, again and again," she said, "Eventually I started making up a different answer every time he asked just so I could preserve my sanity."

Gandy's husband Tom died of dementia in 2017, but she tells caregivers it is important to find creative ways to cope. Topping the list of coping skills is taking a break.

"Put on some earbuds and just zone out," Jacobs said. "You don't have to be fully attentive all the time." Just as important is staying connected through support groups, virtual meetings and other means. Caregivers should seek help before they feel burned out, Irving said. "You don't want to wait until you are at the end of your rope," she said. "If you wait until you're feeling overwhelmed, it is so much harder to make the calls to get help."

Fink said that it is essential for caregivers to engage in some form of self-care.

After a month of isolation, Kay Dungan dropped her husband off at adult day care and relaxed for a few hours. "I try to keep life as normal as possible, not that I remember what a normal life is really like," she said. "But day by day, you just do it."

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