

## HOMELESS HOUSING

A growing movement across the nation has seen tiny houses sprout up in an effort to help the homeless. Local homeless advocates share their views on the idea. SD4

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# IN DEPTH

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SAN DIEGO NEWSMAKERS, IDEAS + OPINIONS



Alford Claiborne rekindled his love of marathon running after putting it on hold while acting as a full-time caregiver.

NELVIN C. CEPEDA U-T

# Life after caregiving

Rebuilding after a loved one's death can be a challenging task for a family member who provided full-time care

BY MICHELE PARENTE

**F**or the 13½ years he was the full-time caregiver for his wife, Rita, through all the havoc and heartbreak caused by her early-onset Alzheimer's disease, Alford Claiborne, 71, needed patience, fortitude and a really good calendar.

As his wife's nurse, cook, bather, bill payer, meds dispenser, physical therapist, driver, doctor's appointment-keeper and medical bureaucracy navigator, Claiborne over the years developed the organizational skills of an air traffic controller.

He created a meticulous system with laminated pages, spiral notebooks, pocket folders and daily planners so he could track the snowballing number of caregiving responsibilities and record every cheerful milestone of her slow disintegration.

Rita died at the couple's Encanto home on March 13, and in the months

since, Claiborne has been trying to reclaim the second life lost to the disease — his.

A lifelong marathoner, he ran his first race in years last month in Dallas. He's taking care of his own long-neglected and newly diagnosed health issues. He's lost nine of the 24 pounds he put on, is leading a men's support group at Alzheimer's San Diego and is spending leisure time with his adult children.

Sitting for an interview on his living room couch recently, Claiborne strained to remember the name of a free Shakespeare production he went to a few months back that was put on by the Old Globe at a local community center.

Frustrated by his clouded memory, he reached for what has become a trusted tether to reality: a paper organizer.

"The calendar," he said, with a sigh, "looks a little different now."

For Claiborne, and the estimated 650,000 unpaid family caregivers in San

SEE CAREGIVING • SD2

Last in a series on the challenges facing family caregivers.

## GOOD WEEK / BAD WEEK Your news score card

### GOOD WEEK

**Mike McCoy:** Despite a stinky season, the Chargers head coach is retained for 2016. The bags aren't packed, but the baggage remains.



**College hopes:** New state laws will help lower textbook costs, give homeless students and foster youth housing during breaks and make it easier for high schoolers to earn college credit. Happiness 101!

**Aztecs:** The NCAA closes its case against SDSU after finding no rules violations in the men's basketball program. Play on, gentlemen.

**Andrew Viterbi:** The Qualcomm co-founder will receive a \$500,000 prize



for creating the algorithm that helped make digital communications possible. A thumbs-up emoji to you, sir.

**SeaWorld:** The marine park settles worker safety citations alleging it failed to protect trainers working with killer whales. Humans and orcas, what could possibly go wrong?

### BAD WEEK

**Weather humor:** The first El Niño storms of the season bring flooded streets, waterlogged homes and a deluge of drought irony. And yet, we're not laughing.

**Wall Street:** Worries about China make the first trading day of the year the Mother of all Mondays. Where did Santa leave the aspirin?



**Winston Shepard:** The SDSU basketball player returns from a road trip to find that his apartment was burglarized. But they can't take the Utah State victory away from him.

**Gun math:** As President Barack Obama announces modest gun restrictions, new federal data show that 2015 appears to be a record-breaking year for gun sales.

**Music history:** Groundbreaking French composer and conductor Pierre Boulez dies at the age of 90. A moment of silence? Non!

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PHOTOS BY NELVIN C. CEPEDA U-T



COURTESY PHOTO

## CAREGIVING Intense role can be hard to let go of

FROM SD1

Diego County, assisting a loved one stricken by disease, impaired by a disability or weakened with age can be an all-consuming undertaking. And the long-term repercussions of that role aren't necessarily lifted with the death of the person being cared for.

Numerous national studies and interviews with caregiving experts and dozens of San Diegans doing that job every day reveal that whatever shape caregiving takes, it can exact a severe physical, emotional and financial toll and rupture family relations beyond repair, particularly when stretched out over years.

Caregivers can face everything from depression to lost jobs, they sometimes turn to substance abuse to alleviate the stress, and they can deplete their nest eggs to pay for the care. Compounding those hardships with loss, grief and possible regret and guilt, can make the transition to life after caregiving even more difficult.

"For all that time while this has been going on, when you couldn't catch your breath ... now how do you move on?" said Lorie Van Tilburg, executive director of the Southern Caregiver Resource Center, the largest nonprofit caregiver support agency in San Diego County. "Caregiving can consume your identity," she said. "Maybe you've lost friends or money, your health has suffered, and now you've got to move yourself forward, all the while you're exhausted. How do you pick yourself up?"

Initially, Claiborne couldn't; he said he slept for weeks after Rita's death.

"I've been saying 'I'm so tired' since 2012 — I'm tired of saying 'I'm tired.' But I know it's OK to be tired for so long. I earned my tiredness."

Early on, Claiborne was projecting the same brand of stoicism that had earned him praise and recognition from local officials, as well as caregiver and Alzheimer's organizations. Just four days after Rita's death, he sat in the front row at the County Administration Building to attend a Board of Supervisors meeting as a show of support for the county's Alzheimer's Project.

From the dais, Supervisor Dianne Jacob expressed her sympathy for his loss. After the meeting, he was met with hugs and handshakes. "I'm still kind of stunned," he said at the time. "But both Rita and I are at peace now."

Over the next few months, however, peace would prove elusive. As Claiborne mustered the energy to rebuild his life, he was filled with self-doubt.

"One of my biggest challenges and fears was, was I losing my sanity? Because what I did all those years was insane," he said.

Had he been a martyr, he thought? Should he have paid to have someone care for Rita every day? Would that person have done a better job? Would she have lived longer? Would his life be less precarious now?

Working through those emotions, he has answered those questions.

"Here comes the martyr again," he said. "No one could have done for Rita — and me — like I did."

### Demographics of caregiving

Over the course of six installments, this series has aimed to illuminate the challenges facing family caregivers. Their ranks are swelling across the country — a 2015 analysis by the national Family Caregiver Alliance estimated the number at a staggering 65.7 million — as America ages and post-9/11-era service members return home afflicted with an unprecedented level of physical and psychological problems.

Whether done out of love, obligation or stark necessity, the often overwhelming job of family caregiving is dis-

proportionally shouldered by women, who make up 82 percent of that population. They are more likely to be daughters, specifically the oldest daughter, in the baby boom generation caring for one or both aging parents, while working full-time. Being in her late 40s or early 50s, the typical caregiver is often also a parent, landing her in what's known as the sandwich generation.

Alford Claiborne, who was the subject of this series' first part, is the exception to that demographic, even though his situation was common. About 80 percent of long-term care is provided by a family member in the home and 14.9 million people are caring for someone who has Alzheimer's or other dementia, according to the Family Caregiver Alliance. The county of San Diego estimates that 60,000 residents are living with Alzheimer's or other dementia, and they are being cared for by approximately 136,800 spouses, adult children or other relatives.

In the military community, there are about 5.5 million family members taking care of a veteran, 1.1 million of them from the post-9/11-era, more than 40 percent of whom are between 18 and 30 years old. Predominantly young military wives with small children, these caregivers not only often lack the maturity and life experience required for the role, they potentially face having the caring responsibilities into their old age.

For them, there will likely be no life after caregiving.

### 'That would make me happy'

The period immediately following the death of the person being cared for can be one of the more challenging chapters in a caregiver's journey.

To an outsider, it wouldn't seem difficult to transition from caring for someone 24/7 to not. But in many cases, it's because it was 24/7 that the role is so hard to let go of.

"The loss of the role of caregiver, especially in the long-term, for 10 years or more — when your life be-

**TOP: Alford Claiborne says it took time for him to rebuild his life after the death of his wife.**

**LEFT: Alford Claiborne holds a photo of his wife, Rita, taken before her Alzheimer's diagnosis in 2001.**

**RIGHT: Alford Claiborne ran his first race in years last month in Dallas.**

**"The loss of the role of caregiver, especially in the long-term, for 10 years or more — when your life becomes that, your identity becomes that, your sense of purpose becomes that — you get lost. And when you go to find yourself again, you're no longer the same person, so you're redefining yourself and redefining yourself."**

**Andrea Cangiano** • director of clinical services for the Southern Caregiver Resource Center

comes that, your identity becomes that, your sense of purpose becomes that — you get lost," said Andrea Cangiano, who, as director of clinical services for the Southern Caregiver Resource Center, heads a team of case managers who work directly with family caregivers.

"And when you go to find yourself again, you're no longer the same person, so you're redefining yourself and redefining yourself."

Those who have left the workforce may have difficulty getting a new job; warring siblings who came together for the sole purpose of helping their parents can split apart again; newfound free time may be hard to fill with meaningful activities; even feelings of relief and excitement over having their lives back can induce guilt.

Time and possibly counseling can help, but Cangiano said caregivers have to kickstart their lives: "It's like pushing yourself out of depression."

Life after caregiving isn't all bleak, experts said. There's comfort in knowing you did all you could for someone you love. There are new skills you've acquired, like planning and organization, that can be useful at home or in the workplace. You can take pride in figuring out how to wrangle the health care system and recognizing you have more resilience and inner strength than you ever imagined.

Jerry Bridge, 58, a motivational speaker in Carlsbad, was a caregiver for his mother and brother, who are now both deceased, and his father, 91, who lives in the Brookdale Senior Living Center in San Marcos.

During that time, Bridge kept a journal, writing down what he was going through and how he was coping. Those cathartic thoughts became the basis of a book, "Who Cares? The Give and Take of Family Caregiving."

"Keeping a journal was the only thing I could do sometimes from getting completely depressed," he said.

One of the lessons others can take from him is the im-

portance of keeping a sense of humor, even through all the caregiving craziness.

"If you can laugh at all, there's no downside of it. ... It relieves stress."

Melissa Collins, 59, a real estate agent from Mission Hills, took a hands-on approach after her father, retired Navy Adm. Frank Charles Collins Jr., passed away.

She had fond memories of how her father, who had dementia, was lifted by the music, activities and human interaction during his visits to the Glenner Memory Care adult daycare center. She started volunteering a few months after he died to share what she learned and give back.

"What I really remembered about my father was he loved people, how he loved for us to hold his hand. I know a lot of people who don't have the love and support that my dad did," Collins said.

She wound up spending time at a residential home with a woman who had early-onset Parkinson's.

"She was just delightful. She'd love to sing. I would do her hair and makeup, just girly stuff. Her husband would take us out to lunch. He wanted her to have that experience. So that's what I did."

And she felt closer to her dad for doing so, Collins said.

For his part, Claiborne now has a regular commitment on his calendar to lead a men's support and discussion group at Alzheimer's San Diego.

"I was the most celebrated caregiver in San Diego," he said with a laugh, "and I'm a philanthropist now," referring to donations he has given to the Alzheimer's organization and the Southern Caregiver Resource Center.

"What I did was so hard and if I can make it easier for someone else, that would make me happy. That would make Rita happy."

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