

How can you live well after being diagnosed with dementia?



The Alzheimer's Association in California estimates that 690,000 people aged 65 and older are living with Alzheimer's, and almost 12 percent of those aged 45 and over report worsening confusion or memory loss known as "subjective cognitive decline." (Illustration by thinkstock.com)

By **TANYA WARD GOODMAN** | Orange County Register

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Bonnie Erickson is an avid hiker who enjoys camping with her extended family. She hunts for petrified wood and Montana Agate along the Yellowstone River near her home in Billings, Mont., often incorporating her found specimens into handcrafted jewelry. These relaxing activities supply a counterpoint to a schedule of speaking and advocacy that defines her role as founder and board president of the National Council of Dementia Minds. It's been five years since she was diagnosed with vascular dementia.

"Once I came out of the darkness," Erickson says, she had one question: "Do I embrace this and live well with it, or do I let it consume me and drag me down?"



According to 2020 statistics used by the Alzheimer's Association, in California, 690,000 people aged 65 and older are living with Alzheimer's, and 11.7 percent of those aged 45 and over report worsening confusion or memory loss known as "subjective cognitive decline." More than half of these individuals have not voiced their concerns to a doctor. In Orange County alone, Alzheimer's disease is the third cause of death, with nearly 12 percent of older adults aged 65 and older reporting a diagnosis of Alzheimer's disease or dementia.

While it may be difficult to move forward, it can be helpful to know that many of those living with and around the disease are working hard to light the way.

"When you hear the word dementia," says Brenda Roberts, co-founder and executive director of The National Council of Dementia Minds, "you go into end-stage thinking right away."

After her husband, Mark, was diagnosed with early-onset vascular dementia, Roberts turned to social media for support. "There were all these people talking about how horrible their person was, and I thought, 'Wow, is nobody living well with dementia? Is nobody happy?'"

More than 40 years of experience in the human service field working with older adults with disabilities and a position as director of Quality assurance and education for Michigan Assisted Living Association had not prepared Roberts for encountering her own husband's diagnosis. Undaunted, she enrolled in caregiving training seminars and certificate programs.

"I still wasn't getting what I wanted," she says. "So I started talking to people with dementia, and then I got it."

Inspired by these conversations, she created a conference for health care providers featuring a panel of those living with progressive neurocognitive disorders. "It's too easy for professionals and caregivers to take over," she said.

In 2019, she recruited a group of eight volunteers, including Bonnie Erickson, to create the first of what would become an ongoing series of educational panels. By 2021, this group, known as "The Originals," had presented to over 3,000 people in four countries and formed a nonprofit organization. Currently, members from 18 states, ranging in age from 45 to 85, participate in a growing number of support groups. Together, they've produced video presentations on a variety of topics, including diet and exercise, how to talk with your doctor, and living well.

"A diagnosis doesn't signal end of life, but signals a change of life," Steven Barbieri says. "You need to find new normals."

Barbieri, board treasurer and founding member of Dementia Minds, has been living with chronic traumatic encephalopathy (CTE) for over 10 years. He explained that when dressed for work as a Wells Fargo district manager, injuries sustained during a lifelong martial arts practice were invisible to physicians. It took what he calls "a life conversation" with an attentive doctor before he was seen as more than a suit.

Like Erikson, he's found meaning and purpose in education and advocacy for person-centered dementia services. "Nothing about me, without me," he says.

Alzheimer's Orange County attempts to take this philosophy into account in all aspects of programming. As the independent nonprofit celebrates its 40th anniversary, it continually works to connect with individuals and their loved ones on a dynamic and personal level.

"We want to keep celebrating people for all of their lifetime achievements and not focus on the losses of the disease," says Kim Bailey, programs and education specialist. Support groups, educational opportunities and social activities, such as outings at Bolsa Chica Wetlands or the Memories in the Making art series, serve people with dementia and their care partners.

"I love having meetings with other people in the same situation," says Kathy S., who has a diagnosis of Lewy body dementia. Kathy, who prefers to remain anonymous, describes Alzheimer's Orange County support groups as a place to "cry together and laugh together," but also a space to explore life in the present. For Kathy, this means connecting more deeply with family. When an Ancestry.com profile turned up previously unknown relations, she traveled to meet them. She found more in common than expected.

"My uncle's wife has dementia," she says. "I saw her in the kitchen going around in circles, not being able to function, so I went and said OK, you do this, I'm going to do that. We helped each other and it was great."

Kathy's visual-spatial issues have increased her anxiety and often make it difficult for her to use escalators and moving sidewalks. Her husband, Sam, takes advantage of elevators and makes a point of arranging to preboard, helping to limit overwhelming sensory input. Both he and Kathy have found the world to be a welcoming one.

"You hear all the bad things in the news," Kathy says, "But I'm not afraid to go places because I know if I say I need help, someone will come and help me whether they know me or not."

Anthony Copeland-Parker, author of "Running All Over the World: Our Race Against Early-Onset Alzheimer's" (Newman Springs Publishing, 2021), finds that travel not only cultivates optimism about his fellow humans, but is also a daily practice in socialization and



When his partner, Catherine, was diagnosed with younger-onset Alzheimer's disease, they decided together to focus on a mutual passion for long-distance running. Taking an early retirement, they sold their house and set out. Over the last eight years, the two have traveled to 81 countries on all seven continents and participated in at least one half-marathon in thirty-five countries.

"They talk about the importance of routine," Copeland-Parker says. "Well, our routine is travel."

His book began as a blog he used to update family and friends. "She's OK," he says, "is not a good enough answer."

Later this narrative became a kind of external memory for Catherine. "Now," he explains, "we listen to the audiobook, and she gets a smile on her face because it's a familiar experience. You might forget a dinner, but you're less likely to forget dinner at the Eiffel Tower."

Picking up and moving every four or five days takes planning and organization, Copeland-Parker admits. "I'm a pilot," he says, "trained to expect the unexpected and figure things out on the fly." This means relying on Uber or Lyft and finding local help to give him a little break. He's become adept at "MacGyvering" hotel rooms to keep Catherine safe and comfortable and has purchased an adult stroller they've dubbed "The Cat Mobile." She might walk a bit and rest a bit. "We like to cross the finish line hand in hand," Copeland-Parker says. "Cat started out being a lot faster than me, but she always waited, and now, I wait for her."

Flexibility and unwavering curiosity nudged Gus Rogerson to move virtually beyond the walls of his home when he opened a Facebook account. In his first post, the poet and former artistic director of The 52nd Street Project, a New York nonprofit, quoted a line from E.M. Forster's "Howards End." "Only connect," he wrote, wishing that "all of my family and friends understand what is happening to me with kindness and witness."

Since his diagnosis with younger-onset Logopenic variant Alzheimer's and aphasia, Rogerson has been collaborating with filmmaker Michelle Memran, whose 2018 documentary, "The Rest I Make Up" chronicled her friendship with playwright Maria Irene Fornes. The two meet and write together over Zoom. In prose and poetry, Rogerson has described the feeling of being on stage, the birth of his daughter, things he has lost and things he has found. Memran provides prompts that often arise organically from her own questions, their previous conversations and shared situations. Rogerson's succinct reasoning for wearing bright clothing has sparked an ongoing dialogue. "Diagnosis dark," he said. "So color."

The only constant is change, but for those living with dementia, this process occurs more rapidly. Understanding limitations and developing "workarounds" become part of living well.

Steven Barbieri wears sunglasses to disguise the fact that he often closes his eyes to limit distractions and make it easier to find words. He's helped his wife to understand that, in a restaurant, sitting with his back to the wall improves his concentration. When Kathy S. gets discouraged, she finds comfort in coloring or pulling weeds in the backyard. "Don't waste your time," she says. Bonnie Erikson has dropped the phrase "I forget," preferring instead, "a glitch in the Matrix." Choosing her own definition allows her to move on.

"I just make light of it and start over," she says. "I'm not one to give up."

For information about online support groups or to schedule a presentation, contact National Council of Dementia at dementiaminds.org

Learn more about dementia-related services from [Alzheimer's OC](#).


There are many different types of dementia, including Alzheimer's, Vascular dementia, and Lewy Body dementia. An accurate diagnosis can help those living with dementia and their care partners come up with personalized strategies and accommodations. Find out more [here](#).

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