

Alzheimer's walk this Sunday

Event supports nonprofit that responds to needs of the afflicted

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North Jersey Record
USA TODAY NETWORK - NEW JERSEY

Imagine you are a child again. You open your bedroom door and it's empty. All your toys and familiar furnishings are gone, sparking confusion and fear.

That's the only way Sandy Czarkowski can possibly think to describe what it may be like to have Alzheimer's disease. She knows because she cared for her husband Casimir, who suffered with dementia before his death earlier this year.

"Alzheimer's takes your soul. It robs you of everything," Czarkowski, a Closter resident said. "That must be so lonely for the person to a point, and then they just don't know what's happening – how is that possible?"

Czarkowski and other caregivers across North Jersey have found support and hope through Alzheimer's New Jersey, a nonprofit that responds to the needs of people affected by the disease.

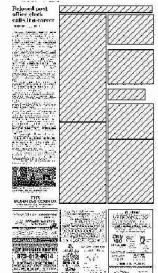
On Sunday, hundreds are expected to gather at Bergen Community College for a fundraising and awareness walk hosted by the organization. It's one of several events state-wide that help provide programs and community partnerships to assist people who are suffering from the disease and their caretakers.

In New Jersey, about 180,000 people have Alzheimer's or other forms of dementia; 600,000 are impacted by it.

A significant percentage of the state's population is over age 65, said Ken Zaentz, president and CEO of Alzheimer's New Jersey. Because age is the greatest risk factor for Alzheimer's, though not a normal part of the aging process, it's a big problem in New Jersey, he said.

The same appears to be true throughout the country. According to the national Alzheimer's Association, 5.7 million Americans are living with Alzheimer's. By 2050, that number is expected to rise to nearly 14 million. Caregivers say contributions toward research, like Microsoft co-founder Bill Gates' recent announcement that he will invest \$100 million toward studies, are encouraging. But the in-the-moment practical support that Alzheimer's New Jersey offers is key.

"It's a constant adjustment," Czarkowski said of caring for someone with dementia. "You start out very optimistic, but eventually you realize you can't make up for what they're losing so quickly and that's a very sad thing."



That's when reaching out for help is necessary. Czarkowski and other caregivers say they don't know what they would do without Alzheimer's New Jersey.

'A subtle, hideous disease'

Czarkowski's husband of more than 50 years was outgoing, capable and confident, his wife said. But as the lifelong athlete, classically-trained pianist and engineer aged, Casimir appeared on the crabby side, perhaps not enjoying life as much - at first, she suspected it was just part of the normal aging process.

"You really don't know - it's such a subtle, hideous disease," she said.

He was diagnosed with dementia in 2016 and died two years later at age 76. Czarkowski is still reeling from Casimir's quick decline and death - she said it's like someone threw her against the wall and then said, now carry on.

But through Alzheimer's New Jersey, Czarkowski has forged friendships with other caregivers via support groups and was able to better understand the disease through educational programming.

"They made Casimir feel whole when that was important, and they made me feel whole by the support offered at caregiver meetings," she said.

Donna Telesca, now a close friend of Czarkowski's, said the organization has helped her and her husband, Sal, who suffers from early-onset dementia, navigate a terrifying path.

"You could've had the worst morning you've ever had, but you leave feeling so hopeful and refreshed," Telesca, of Hackensack, said of meetings. "If [the organization] wasn't there, I would have nothing."

Before he started showing symptoms of dementia, Telesca said Sal, 65, had "a very OCD personality" - everything was always buttoned up and he was very capable. Then, he forgot to pay their taxes and began falling asleep often during the day.

The dementia diagnosis came as a blow, particularly since Sal had helped Telesca care for her father, who also suffered with the disease.

"When you see that and then it's on you, it's really an inconsolable time in your life," she said.

Telesca said Alzheimer's New Jersey and the services they offer has been life-changing. She's hopeful more awareness will be brought to the disease, helping to keep those suffering active, part of the community and feeling normal.

Zaentz said the support Alzheimer's New Jersey offers caregivers is incredibly important.

"The disease can be so isolating that many times the caregiver loses their connection to their circle of friends, not because people don't care, but because as a caregiver you're dealing with this long-term illness," he said. "Sometimes your friends become the people

you connect with in a support group.”

Joe Barbara, whose mother Peggy has Alzheimer’s and lives with her son and his family in Upper Saddle River, said at times his mother’s dementia has left him frustrated, then guilt-ridden.

Peggy was once the secretary at Barbara’s Catholic grade school. She basically ran the school, he said; when she left they hired three people to replace her.

“She was fantastic. She did everything – to see her not be able to do anything, not even be able to put a sentence together, it just breaks your heart,” he said. “It’s excruciating.”

Alzheimer’s New Jersey is a place Barbara said he can turn to and understand that he’s not alone in his sadness and frustration.

Zaentz said the organization wants to help caregivers understand that they can still make the best of every day with their loved ones and learn to live in the little meaningful moments.

“As hard as this is, while the person may begin to drift away from memories and connections they once had with their loved ones – that doesn’t mean that they aren’t capable of a loving relationship,” Zaentz said. “The facts may be out the window, but that doesn’t mean they don’t understand that you’re someone that’s emotionally important to them.”

Registration for the Norther Regional Walk to Fight Alzheimer’s will begin at 8:30 a.m. Sunday. The 2.5 mile walk begins at 10 a.m. and will be held under the parking deck in Parking Lot A at Bergen Community College.

“Alzheimer’s takes your soul. It robs you of everything.”

Sandy Czarkowski
Closter resident



Sal and Donna Telesca. PHOTO COURTESY OF DONNA TELESKA



A crowd gathers for the fundraising walk during the 2016 event. PHOTO COURTESY OF ALZHEIMER'S NEW JERSEY