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Changing ‘the tragedy narrative’: Why a growing camp is promoting a more joyful approach to Alzheimer’s

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Tom Misciagna and his wife, Peggy, have a nickname, Ollie, for Alzheimer’s, the disease Tom was diagnosed with seven years ago at 57. Ollie is a presence they didn’t invite into their lives, but they’re making room — and having fun — with him. (Pete Marovich/For The Washington Post)

Tom and Peggy Misciagna were sitting in their Manassas, Va., home recently, talking about the children they adopted overseas in the 1980s, when Tom, 64, misremembered a major detail.

“We got two kids out of India — ” he said.

Peggy, 59, chimed in. “Philippines.”

“Oh yeah, Philippines,” said Tom, a retired CIA officer. He grinned wryly at his wife. “That’s Ollie talking.”

Ollie is their nickname for Alzheimer’s, the disease Tom was diagnosed with seven years ago. For the Misciagnas, Ollie is a third presence in the house, one they never invited in. But since he’s here, they’re making room for him. And though it might seem counterintuitive, they are even trying to have fun with him.

That approach — giving the illness a nickname, smoothly zigging after hitting a zag — puts the Misciagnas in a growing camp of people determined to approach dementia care differently, coming at it with a sense of openness, playfulness and even wonder.

It is in stark contrast to earlier generations of Alzheimer’s patients and their caregivers, who saw the disease as something to be hidden. Even now, fewer than half of Alzheimer’s patients are told they have it, according to a 2015 Alzheimer’s Association report, and a 2012 study found it surpassed cancer as the disease Americans fear most. It has been swathed in shame, stuck in what Bill Thomas, a geriatrician who is working to change attitudes about old age, calls “the tragedy narrative.”

“The main framework America has available to contend with this is . . . that it’s a terrible, destructive ride all the way down and then you die,” he said. “While factually true, that is extremely unhelpful to families and elders.”

Family members often try to nudge a loved one back toward getting facts right or remembering things correctly, but as the disease progresses this can turn their daily interactions into grim, and increasingly frustrating, battles.

Without dismissing the difficulties of the disease, especially in the late stages, Thomas and others are promoting a more adaptive approach, which they say can help caregivers and patients alike. It involves a lot of flexibility and willingness to expand one’s ideas of how things are supposed to be — even, crazy though it might sound, to see Alzheimer’s as a kind of gift.

Too much attention is focused on medicalizing the disease, said Mary Fridley, co-creator of a workshop called “The Joy of Dementia (You’ve Got to Be Kidding!)” at the East Side Institute, an alternative psychology and education research center in New York.

“Dementia is enormously painful,” said Fridley, who has written about caring for her mother, who had Alzheimer’s and died a year ago. But, she added, “I truly believe it is an opportunity, if people so choose, to be improvisational, to be silly, to play, to free ourselves from the constraints of truth and knowing and assumptions.”

A 2016 pilot study in a Canadian nursing home found that dementia patients’ behavioral and psychological symptoms declined significantly and their quality-of-life scores improved significantly after 12 weeks of visits by “elder-clowns” who engaged with them using humor, empathy and improvisation. Caregivers, too, appear to benefit: A 2016 Australian study found

dementia-care staff with positive attitudes and “person-centered” strategies felt more competent about their ability to provide care.

Although large-scale studies on positive approaches to dementia have yet to be done, a growing number of groups around the United States are embracing them.

Thomas’s organization, ChangingAging, has a traveling show called “Disrupt Dementia” that explores the emotions associated with dementia. And in Seattle, a collective movement known as Mementia facilitates social gatherings at coffee shops, museum tours, zoo walks, and even gibberish conversations for people with dementia and their caregivers.

That is familiar to Fridley. “With my mom, especially as she began to lose, quote-unquote, her capacity to speak, she was babbling and the words were nonsensical,” she said.

Rather than staying confined to a fixed idea of what language is, Fridley stopped worrying about it.

“Sometimes, we created a poem together. She would say something and I would say something that, quote, rhymed and then she would say something that rhymed, like, ‘I’m dying;’ ‘You’re dying;’ ‘I’m dining;’ ‘I’m dining before I’m dying.’ ”

Jennifer Carson, director of the newly launched Dementia Engagement, Education and Research program at the University of Nevada at Reno, encourages this kind of engagement.

“Alzheimer’s can be a liberating event, an opportunity to fly,” she said. “This is in no way to dismiss the pain and suffering that comes from dementia, but to understand that a lot of that pain and suffering comes from the response.”

Carson believes much suffering comes from the social response after the diagnosis, what she describes as being treated as if you’re no longer there. “Tell someone they have dementia and then ignore them: That’s the suffering, way more than the tragedies that are intrinsic to dementia itself.”

That was the experience of Brian LeBlanc of Pensacola, Fla., who was diagnosed with Alzheimer’s four years ago. People would walk up and “turn to whoever I was with and say, ‘How’s he doing?’ I’d turn to them and say, ‘I’m doing pretty good and I can still hear you.’ ” he said.

LeBlanc, 58, was painfully familiar with the disease — his mother, grandfather and great-grandmother had it, and receiving his diagnosis was devastating. But, he said, “I did not want to stay in that dark place.”

His mother had never wanted to talk about her Alzheimer’s and became withdrawn after her diagnosis. But LeBlanc’s background was in public relations and marketing, so he started doing what he knew best: traveling and speaking publicly, hoping to educate people about how Alzheimer’s feels from the inside.

From the early days of his diagnosis, LeBlanc used humor as a coping mechanism. After he learned he had the disease, a friend sent him a picture of a T-shirt that read:

“Roses are red

Violets are blue

I have Alzheimer’s

Cheese on toast.”

“I thought that was the funniest thing,” he said. “Those are the type of things that keep me going. I get enough of the stigma of people saying I don’t look like I have Alzheimer’s. But it’s the people who are really my friends who will stick with me and joke and say, ‘Hey, do you have the 20 bucks you owe me?’ And then I have to stop and think, and they’ll start laughing.”

Rethinking 'idea of normal'

In a ballroom at a volunteer firehouse in Walkersville, Md., in November, Karen Stobbe instructed the audience, which included professional and family caregivers, to pair up. Some were there with spouses who had dementia. Stobbe showed them how to mirror each other’s body movements, letting their partners lead, until the whole room was a dance of arcing arms and cocked heads.

Stobbe, 54, has spent a third of her life as a caregiver, first for her father, who had Alzheimer’s and died in 2000, and then for her mother, who had the disease for 17 years and died last March.

She had trained as an actress, but in caring for her parents, she found that theatrical improv skills also worked with them — meeting them where they were and following their cues no matter how unexpected they were.

Now, as part of *In the Moment*, a nonprofit Stobbe started that trains people in interactive dementia care, she addressed the 150 members of the Greater Maryland chapter of the Alzheimer’s Association.

Don’t deny; agree, she told them. Don’t argue. Flowing, rather than resisting, is the key to fruitful interactions. When a patient is asking for something unreasonable or impossible, rather than saying “no,” say “yes, and” — and then insert a suggestion that is feasible.

“If someone says, ‘I want to go home,’ you can say, ‘Yes, and tell me about your home,’ or, ‘Yes, and it’s a little chilly; let’s get a sweater,’” she said. “What it is, is a Band-Aid for right then. It’s calming her down and saying, ‘Yes, I hear you.’”

For caregivers, staying positive means letting go of expectations of how things should be, Stobbe said. “We have this tendency where we want that person to be back in our world,” she said. “We

think it's not normal so we want them to stop. If someone's sitting at the table ripping up napkins and they're getting joy out of it, why not let them do it? Just because it's not our idea of normal?"

Instead, she said, it can be rewarding to get to know their world.

So, if they see a duck on your head or monkeys outside the window, playing along with "the things that come out of their mouths because the edit button is off" can allow everyone to relax and have fun. "Laugh or sing with them," she said, "and they see it's okay."

Fridley encourages people to view the nonlinear, often fictional dialogues of Alzheimer's patients with the same expectations they would have of poetry. "I think that almost everyone agrees that the experience of writing and reading poetry differs from the experience of writing and reading a newspaper," she said. "Poetry isn't truth-laden. I think most people see it as playing with language, and people accept it for that and love it for that, because it allows us to connect in noncognitive ways."

After all, she said, there is plenty that we do in everyday life that doesn't totally make sense. "We dance silly dances, we look at the moon, we fall in love, and all of those things are wonderfully unreasonable."

Making things more fun

Recently, Tom and Peggy Misciagna were at Bowl America on Mathis Avenue in matching black polo shirts with the Iron Eagles, a mixed Friday morning league. Tom, a solidly built man with neatly trimmed salt-and-pepper hair, picked up a ball and leaned in, sending it crashing into the pins — the last frame of the day.

It wasn't quite a strike, but it was close. His teammates cheered.

A little smile played on his face as he joined his wife on the bench.

"I came on strong, right?"

"Good game," she said, and their fingers linked for a second.

It was lunchtime. At Captain D's on Centreville Road, they ordered their usual three-piece battered-fish platter and talked about their life and the ways his disease has changed it. How it was hard at first for him to tell people he had it. How now, when they tell the story of how they met, he needs her to fill in key details that he once knew by heart.

Since his diagnosis, the couple has made a point of trying to have fun together. Tom has taken up new activities such as darts and coloring books. He'd never danced before; now, he and Peggy go square-dancing. He'd never played a musical instrument, but he took up the violin. And they joined the Forgetful Friends Chorus, for people with dementia and their friends and caregivers, though he had never sung before.

“Wait a minute, wait a minute,” he cut in. “When I was an altar boy, I had to sing.”

“In Latin,” Peggy added.

He grinned. “In Latin, no less.”

Peggy is grateful for Tom’s ability to joke about his failing memory. Still, she has to constantly navigate how to talk with him about his limitations. “It’s almost like a child — if you tell a child, ‘You have to do this,’ well, they’re not going to do it. . . . If we’re out doing the lawn and I keep saying, ‘Tom, do this, Tom do that,’ at some point he becomes a little rebellious, like a child. If I ask him to get some leaves, he’ll say, ‘No, I’ll do that later.’ A few minutes later, he’ll say, ‘What can I do to help?’ and I’ll say, ‘Can you go get those leaves over there?’ and then he’ll go over and do it.”

Keeping things loose and flowing is something Peggy does to make her own life easier. But it also puts Tom at ease. And it makes things more fun.

Like the day he was in the bathroom shaving and she heard him yell, “Oh my gosh, what have I done?”

He appeared in the doorway — with only one eyebrow.

“Can you fix it?” he asked.

“Nope,” she said, unable to stop laughing. “Just shave off the other one. It’s only an eyebrow.”