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Come Together

Actors Jill Eikenberry and Michael Tucker reflect on how Alzheimer’s disease has made their family bond stronger.

BY LINDA CHILDERS

Jill Eikenberry, 63, and Michael Tucker, 65, are one of Hollywood’s most enduring couples. Best known for their roles in film, theatre, and on the long-running television drama, *L.A. Law*, the two actors have been married for 36 years. They have a daughter, Alison, 40, (by Tucker’s first marriage), and a son, Max, 27. Several years ago, the couple found themselves taking on a new role as caregivers to Eikenberry’s now 90-year-old mother, Lora, who suffers from Alzheimer’s disease.

Eikenberry was concerned when Lora first began showing signs of memory loss in 1998. Although she lived 3,000 miles away, in New York, NY, Eikenberry frequently spoke with her mom on the phone and visited Lora at her home in Santa Barbara, CA. Eikenberry wondered if Lora’s increased confusion and inability to remember things were normal signs of aging or symptoms of a more debilitating problem. “I took my mom to a neurologist. After two days of tests, he said she had ‘frontal lobe syndrome’ but that he couldn’t make a definitive Alzheimer’s diagnosis,” Eikenberry recalls. “My mom was having paranoid fantasies. When Mike and I gave a speech in the Cayman Islands, my mom believed we were there to ‘launder money.’”

Paranoid delusions can be a symptom of Alzheimer’s disease,” says Steven Holtz, M.D., a neurologist at John Muir Medical Center in Walnut Creek, CA. “The course of Alzheimer’s isn’t the same in every person with the disease, but symptoms do seem to develop over the same general stages: mild, moderate, and severe.”

**BRINGING MOTHER HOME**
Over the next eight years, her mother’s cognitive abilities continued to decline. “In addition to forgetfulness, my mom continued having paranoid fantasies,” Eikenberry says. When Lora’s husband (Eikenberry’s stepfather) died, it became apparent to both Eikenberry and Tucker that Lora could not continue living alone in her Santa Barbara home.

“We made the decision in 2006 to move my mom to a retirement community near us in New York that offered assisted care,” Eikenberry says. “We started out having someone check on mom a few times a day, but it soon became clear that she needed full-time care. She became belligerent, partly because she doesn’t hear well.”

Eikenberry found herself in the office of the retirement community on an almost daily basis, struggling to ensure that her mother received appropriate care. “There was no consistency of care, and none of the aides seemed to know how to deal with dementia,” Eikenberry says. “It was incredibly frustrating.”

After realizing that Lora needed more care than the retirement community could provide, Eikenberry and Tucker learned the apartment across the hall from them was available. The timing was perfect; with Lora living in close proximity they could oversee her care with the assistance of professional nursing aides. “It took three months of hell before I found two wonderful caregivers, and one that was less wonderful, through a family assistance network,” Eikenberry says. “I replaced the one woman and now my mom has three fantastic caregivers. They all
love my mother, who feels completely safe with them. She’d be lost without them, and so would I.”

“It’s not unusual to see caregivers become almost extended family members when they are caring for a person with Alzheimer’s,” says Nader Shabahangi, Ph.D., a licensed psychotherapist in San Francisco, founder of the Pacific Institute, and president and CEO of AgeSong, a family-run group of senior communities. “The bonds between the caregivers and the family of the person with Alzheimer’s can run deep.”

Although it helped to know that her mother was in good hands, Eikenberry and Tucker still struggled to cope with the ramifications of Lora’s disease and her increasing bouts of anger.

“People with Alzheimer’s are sometimes prone to anger as they become frustrated and try to cope with losing their independence,” Dr. Shabahangi says. “Instead of arguing with the person, it often works better to agree with them and then to redirect their behavior.”

“When she got angry—which was often—I ran and hid in the other room,” Tucker says.

“I wanted to do the same,” Eikenberry says, “but I sat and held her hand and talked to her for hours trying to convince her that we had her best interests at heart. The worst moment came when she told me I had taken her away from her friends in California and had ruined her life. I told her I would see her every day, and she said, ‘You won’t. You’ll go away and leave me alone.’”

THE EMOTIONAL FALLOUT

Tucker and Eikenberry realized early on that Lora’s illness was impacting everyone in the family and decided they needed to discuss their feelings with each other openly and honestly. Like many spouses of caregivers, Tucker admits to harboring some initial feelings of resentment.

“My resentment stemmed from seeing Jill’s personality change when she was with her mother, which was fine when Lora was 3,000 miles away and we saw her twice a year,” Tucker says. “But when Lora began living across the hall—and failing mentally—I feared I would lose Jill as I knew her.”

While having Lora live across the hall made things easier, the couple also learned that they needed to set some boundaries.

“After we moved my mother across the hall, I started inviting her and the aides over to our apartment daily, and I soon realized that Mike felt invaded,” Eikenberry says. “They now come over for special dinners or occasions, but mostly I go over there. I’ve had to learn to be grateful for Mike’s generosity and not push his limits.”

“We realized we had to get on the same side of this situation,” Tucker says. “I was arguing for our life, and Jill knew she was responsible for her mother’s life. We pulled and tugged a bit until we realized we had to do both: make sure Lora had a good last chapter, while also ensuring that our own current and future chapters were as full and productive as possible.”

Like many adult children of elderly parents, Eikenberry also realized she had some unresolved issues with her mother. Their roles were changing, and Eikenberry sought out the advice of a therapist.

“I realized I was still looking for my mother’s approval even after she was in a state of advanced dementia. I have finally been able to let go of those expectations, and it has helped me to really appreciate who she is now and the time I have with her,” Eikenberry says. “I also realized how much I was still trying to make other people like her, which is something I have been doing since she lost her hearing years ago. As soon as I was able to let go of those expectations, my stress level went way down.”

COMING TOGETHER AS A FAMILY

Shortly after Lora settled in to her new home, Tucker and Eikenberry’s children—Alison, a personal chef and caterer, and Max, a musician—also made the decision to relocate to Manhattan and help their parents care for Lora.

“Everyone in the family took on the caregiver tasks that best suited them,” Tucker says. “Alison cooks all of Lora’s meals, so she’s very in touch with her and her aides at least three times a week. Max used to enjoy visiting Lora almost every day and reading to her. He doesn’t visit as often now that she’s less responsive. I think it’s hard for him.”

Despite taking donepezil for three years, Lora’s health continued to decline. As she watched the inevitable cognitive and behavioral
changes in her mom, Eikenberry found inspiration watching how her mother’s caregivers adapted to Lora’s new reality.

“The biggest lesson came from watching my mom’s aide Marcia with my mom. Marcia never knew Lora the intellectual and political activist, and she doesn’t need her to be that Lora,” Eikenberry says. “She only knows the Lora she is now, and she loves her. This has helped my mom to relax and stop reaching for her former personality, and their acceptance has finally allowed me to accept it too.”

Dr. Shabanhangi, author of the new book, Conversations with Ed: Waiting for Forgetfulness: Why Are We So Afraid of Alzheimer’s? (Elders Academy Press, 2009) believes that families might cope better by trying to view people with Alzheimer’s in a different light.

“When you visit a foreign country you don’t assume that people will be like you and speak the same language,” he says. “It’s the same with people who have Alzheimer’s; how you communicate with someone who has memory loss can help you gain insight you might not learn otherwise. Instead of seeing the person as a liability, try seeing them as a teacher.”

As with many people who have Alzheimer’s, Lora experiences moments of clarity mixed with days where she mistakes her loved ones with people from her past.

“Because of the nature of Alzheimer’s, it’s not unusual for people to have brief moments of clarity mixed with longer periods of forgetfulness and confusion,” Dr. Holtz says. “Normally, if people mistake a loved one for someone else you correct them, but these ‘normal’ ways of interacting don’t work when communicating with a cognitively impaired individual.”

“My mom calls me Lois, the name of her closest sister, and she calls our aide, Marcia, Ethel, the name of her oldest sister,” Eikenberry says. “She refers to her weekend aide as mother. So she believes that she is surrounded by her two closest sisters and her mother.”

“Who she thinks I am is a mystery to me,” Tucker says. “But she’s happy to see me.”

TREATMENTS AND PREVENTION

While there is no cure for Alzheimer’s, numerous medications are available to reduce the symptoms of the disease, says Dr. Holtz. The Federal Drug Administration (FDA) has approved three medications that have been shown to improve memory and slow the progression of Alzheimer’s: Donepezil, rivastigmine, and galantamine have proven beneficial to some patients in the early to mid stages of Alzheimer’s. However, these medications have not proven effective in all patients.

In addition, non-drug treatments, including mental and physical exercise and even caregiver support, are emerging.

Alzheimer’s Disease:
The Basics

The National Institute on Aging defines Alzheimer’s disease as an irreversible brain condition that slowly destroys memory and thinking skills and eventually the ability to carry out the simplest tasks. In most people with Alzheimer’s, symptoms first appear after age 60.

For the 5.3 million Americans living with Alzheimer’s, the golden years lose some of their luster as they wage a daily battle against this progressive and fatal neurologic condition.

According to the Alzheimer’s Association, the number of people aged 65 and older with Alzheimer’s disease is expected to reach 7.7 million by the year 2030.

“There are several significant differences between age-related memory loss and Alzheimer’s disease,” says Dr. Holtz. “People with Alzheimer’s have memory loss that disrupts their daily lives, difficulty completing familiar tasks, and changes in their moods and personality, and they may drop elements of self-care.”

Since depression and mild cognitive impairment can share some of the symptoms of Alzheimer’s disease, Dr. Holtz recommends making a doctor’s appointment to have your loved one evaluated if they are exhibiting signs of memory loss.

The Alzheimer’s Association lists the 10 warning symptoms of Alzheimer’s disease on their Web site and also offers a doctor’s appointment checklist at alz.org/alzheimers_disease_know_the_10_signs.asp.
as proven medicine for the disease, according to many of the latest studies presented at the 25th Conference of Alzheimer’s Disease International held in March 2010 in Thessaloniki, Greece.

Since research has shown that having a parent or sibling with Alzheimer’s can increase a person’s risk of developing the disease, both Tucker and Eikenberry have made lifestyle changes in the hopes of warding off future cognitive problems.

According to research presented by the Center for Alzheimer’s and Related Disorders in Springfield, IL, at their third annual Alzheimer’s Disease Conference in May 2010, lifestyle changes that may reduce risk of Alzheimer’s include lowering high blood sugar, blood pressure, and cholesterol levels; controlling or preventing diabetes; exercising regularly; maintaining a healthy weight; and engaging in socially and mentally engaging activities.

Recommended levels of physical activity include two and a half hours per week of moderate aerobic activity (such as walking briskly) along with strengthening activities (like push-ups, sit-ups, and lifting weights) two times a week.

“My mother died of Alzheimer’s, so it’s something I do think about,” Tucker says. “Since brain exercises have been shown to have some effect in warding off dementia, I do a crossword puzzle every morning and Jill and I are learning a foreign language.”

Eikenberry also enjoys regular exercise, including walking, Pilates, and yoga. “I take supplements for menopausal symptoms, which my doctor said may also help with memory, and I try to meditate daily to relieve stress,” Eikenberry says.

LESSONS IN CAREGIVING

Several years ago, the couple purchased a 350-year-old farmhouse in Umbria, Italy, where they vacation frequently. Italy is a perfect place for a confirmed “foodie” like Tucker, who has written three books about the importance of food in a fulfilling life: I Never Forget a Meal: An Indulgent Reminiscence (Little Brown & Co, 1995), Living in a Foreign Language: A Memoir of Food, Wine, and Love (Atlantic Monthly Press, 2007), and Family Meals: Coming Together to Care for an Aging Parent (Atlantic Monthly Press, 2009). Living part of the year abroad has also given Tucker and Eikenberry an appreciation for how other countries handle eldercare issues.

“The main difference between Italy and the United States is that Americans want to put their ailing and failing parents in a nursing home, and Italians bring their relatives into their own homes,” Tucker says. “This is a generalization, but it does hold true most of the time. The Italians often hire East European women, called ‘badanti,’ who leave their countries to come to Italy and provide 24-hour, live-in care for the elderly at a reasonable price.”

Eikenberry admits that she and her mother never discussed how Lora wanted to be cared for in the event she could no longer care for herself. All of her decisions have been based on wanting to obtain the best possible care for her mom and relying on the advice of eldercare experts.

“I would urge anyone who has a loved one with Alzheimer’s to find some help and support,” Eikenberry says. (See box, “Support for Alzheimer’s Patients and Their Families,” in Resource Central, page 35) “It’s really so hard to manage it all on your own, and the truth is that professional caregivers with eldercare experience can do it better than you can.”

“It can be a bureaucratic maze navigating the eldercare system,” Tucker adds. “We found an eldercare attorney who referred us to a Family Assistance Network in Manhattan that helped us find aids and explore options such as Medicaid.”

Today, Eikenberry’s visits with Lora have evolved from heart-to-heart talks to time spent hugging and holding hands.

“My mom doesn’t wear her hearing aid anymore, and she’s aphasic—she can no longer communicate verbally—so most communication is non-verbal at this point,” Eikenberry says. “I just try to be with her and to enjoy the moment.”

“The most amazing part of this journey was seeing three generations of our family come together around this crisis,” Tucker adds. “No one planned it; it just happened, and we’ve never been so close.”