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By NICOLE WEISENSEE EGAN

Photog

It's a busy weekday night at Los Amigos restaurant in Springfield, Mo., and waitress Daisy Duarte is rushing back and forth between customers. She's also keeping a close eye on her mother, who sits alone at a table. "Watch this," Daisy tells a visitor. "If I put a pen and paper here, my mom will immediately start scribbling." Sonia Cardona does just that. Since she was diagnosed with Alzheimer's disease in 2013, childlike pastimes tend to keep Sonia, a onetime teacher's aide, amused. Daisy, relieved to see her occupied, looks pale and worried nonetheless. "I went to bed at 5 a.m. and got up at 9 a.m. because I can't fall asleep," she admits. "That's been happening the past few days. I'm nervous about tomorrow."

For good reason. The following day Daisy was due to get life-altering news: the results of a genetic test that would reveal whether she, like her mother, carries a gene for early-onset familial Alzheimer's, a rare form of the devastating illness (see box). Seventy-five percent of Sonia's relatives had the

Taking Care of Mom

Daisy does everything for her mother—from hair and makeup ("I like to make her feel pretty") to getting her dressed to bringing her along to her waitressing job. "If I need to get anything done at home, I put *Ellen* on," Daisy says. "Mom loves to dance to it. She talks to Ellen and laughs."

VII; CENTER RIGHT: COURTESY ANDREA PACHI

‘I’m not going to dwell on it. You just have to make the best out of life’

—DAISY DUARTE

disease, and Daisy had a 50/50 chance of inheriting it. Unmarried and childless, Daisy has been her mother’s full-time caretaker for nearly four years and decided to take the scary step “to be prepared,” she says. Though there is no effective treatment for Alzheimer’s, there are drug trials, and “if they’re trying to find a cure, I want to be involved. I have nieces and nephews. I would like by their time to have a cure or at least stop it from being so aggressive.”

In deciding to get tested, Daisy joins a growing number of people who are electing to learn their genetic destinies. But it’s an agonizing decision when the disease in question is one for which nothing can be done. “You can’t unring that bell,” says Robert Green, a geneticist at Brigham & Women’s Hospital in Boston and director of a national study evaluating how people respond to their Alzheimer’s genetic-testing results. “You can’t unlearn it. These are emotional, high-intensity cases.”

On Aug. 7, in the offices of genetic counselor Mary Owen, Daisy got the news she had been dreading: “You have the same mutation as your mother,” Owen told her gently. Daisy put her head in her hands and wept. “I already knew,” she said, wiping her tears with tissues as her mother, who accompanies her everywhere, stroked her back. Sonia didn’t understand the conversation but knew distress in her child when she saw it. “Are you okay?” she asked. Daisy nodded and hugged her tight.

Since that day, Daisy has been coming to terms with what awaits her. She’s been told the positive result means she will get Alzheimer’s by the time she is 65; the average life span after symptoms appear is seven years. Her biggest worry is for Sonia. “She’s everything to me. I’ve got to take care of her,” says Daisy, who sold the sports bar she once owned in order to work shorter hours at Los Amigos and be able to bring her mother along. “I don’t want her in some hellhole.”

Money is tight: Daisy rents the 2,600-sq.-ft. Springfield duplex she shares with her mom and a roommate. Sonia has a $24,000 annual pension. Until

Learning Her Fate

“Obviously this is not what I wanted to tell you today,” genetic counselor Mary Owen said as Daisy’s friend Andi and Sonia comforted her. “But they’ve got a lot of promising things going on in research.” Daisy is now in a clinical trial run by the Dominantly Inherited Alzheimer Network Trials Unit (dianexr.org) at Washington University School of Medicine in St. Louis.


The blood test June 5


The results Aug. 7

'My mom is with me until the day she dies. **I will never put her in a home'**
—DAISY DUARTE

recently neither woman had health insurance. Daisy's niece helps out when she can, but neither of her siblings is in a position to take her in permanently should the need arise. (And so far Daisy is the only one of Sonia's three children who has been tested. Says her brother Juan, 37: "I don't want to know.")

Luckily, Daisy has good friends. "A group of us have let her know we'll be there for her no matter what," says Andi Pachl, 34, a consultant. "If family doesn't step in to care for her mother, we will."

For now, Daisy is trying to make the most of whatever time she has left with her mom. In September Andi and Daisy took Sonia to Las Vegas—a trip her mom had always hoped to take. Mother and daughter take daily walks, have dinners out, go dancing and to pro baseball games and shoot pool, all activities Sonia still seems to enjoy. But she's inarguably slipping. "She talks gibberish—sometimes she remembers me, sometimes she doesn't," Daisy says. "She doesn't know how to get into a car; she talks to her reflection in mirrors. I'm scared for the day when she's bedridden for good. I don't know how much time she has. This disease doesn't tell you."

As for Daisy, she says she forgets little things, like where she left her keys, but no more than she ever did. In November she entered a clinical trial that is testing two different drugs researchers hope might delay Alzheimer's symptoms. "No one has ever survived Alzheimer's, and we aim to change that," says Dr. Randall Bateman of Washington University School of Medicine in St. Louis, the trial's principal investigator. Daisy has also been working with local groups to raise awareness about the disease.

No matter how the rest of her life plays out, she takes great pride in the care she has been able to give her mother. "Her doctor can't believe how well she's doing," Daisy says. "He said he's seen several patients at the same stage she's at, and they were all in nursing homes or bedridden. He said, 'Just keep doing what you're doing.'"

That—along with cherishing every moment—is exactly what she plans. "I have the gene; I don't have the disease yet," she says. "All I have to do is take it one day at a time." ●

Early-Onset Alzheimer's: The Facts

Of the estimated 5.2 million Americans who have Alzheimer's disease, some 200,000 have the early-onset form, according to the Alzheimer's Association (alz.org). Not all early forms are genetic, but experts recommend offering testing to families where many people were diagnosed before age 65. "There are gene mutations that directly cause early-onset," says Susan Hahn, an Alzheimer's expert for the National Society of Genetic Counselors. "Testing can facilitate choices such as whether to have children or pursue a certain career." The disease is the subject of the film *Still Alice*: Julianne Moore's character is diagnosed; her younger daughter, played by Kristen Stewart, decides not to get tested. "I cried through the whole thing," says Daisy, who took her mother to see it.

Stewart and Moore on the set of *Still Alice*.

BOTTOM: JAXN/AKM-GSI

TABLET BONUS! Watch a clip of the movie *Still Alice* starring Julianne Moore