

## Speaking Up and Out About Alzheimer's



"It's a very lonely disease. To watch this person who is your everything be stripped away slowly it's terrible."

-KIMBERLY STEPHENS

Kimberly Stephens' mother, Karen, loved to throw a party. She was famous among friends in the family's hometown of Birmingham, Alabama, as an expert entertainer who never skipped a detail. Even in a crowded room, Karen stood out with her loud and contagious laugh.

"Entertaining was her jam. She was a blast," Kimberly says. "When anyone talks about my mom, they always tell you how much fun she was."

When Kimberly's sister got engaged in 2011, everyone in the family thought Karen would play a key role in wedding planning. But Karen had trouble completing even minor tasks; she also started behaving erratically and getting lost while driving on familiar streets.

"She would redo things she had already done, and then when she realized it, she'd cry," Kimberly says. "She'd call me and say, 'I wake up every day and my life is on the floor, and I have to pick it back up."

Karen was diagnosed with youngeronset Alzheimer's in 2014 at age 61. She's one of four women in Kimberly's family to have the disease. Kimberly's grandmother — Karen's mother — lived with dementia, and Karen served as her caregiver. The same year Karen was diagnosed with Alzheimer's, Kimberly's Aunt Janice on her father's side was also diagnosed with a rare form of Alzheimer's. A few years later, another aunt developed the disease.

The news of Karen's diagnosis was devastating for the family. Kimberly, her father and her three siblings developed a schedule to provide care for their mom but felt lost.

"It's a very lonely disease. To watch this person who is your everything be stripped away slowly — it's terrible," Kimberly says.

At first, the family tried to downplay Karen's condition to protect her from stigma. They soon learned the same heartbreaking cover-up was happening in her Aunt Janice's family.  $\rightarrow$ 





"We are all very close. We're Lebanese. A big, loud family that is in each other's business and always helping each other out, but we weren't prepared to take on Alzheimer's at all," Kimberly says.

The burden of caregiving and keeping her mom's disease under wraps soon became too much, and in 2015, Kimberly began to search for help. She discovered the Alzheimer's Association online and learned about a Walk to End Alzheimer's® event taking place in Birmingham. Through the event, Kimberly saw an opportunity to proactively fight the disease and rally her family around a positive goal that would also encourage them to start openly talking about Alzheimer's.

Kimberly's extended family participated in their first Walk in 2015 under the name Sitty's Angels ("sitty" is Arabic for "grandmother"). Kimberly's mom and Aunt Janice both held blue flowers — a symbol of living with Alzheimer's — at the event's Opening and Promise Garden Ceremony. It was an emotional and empowering moment for the entire family.

"It was our way of telling people what we are doing, to release the stress of it all," Kimberly says. "Walk was my intro to actually talking about the disease, and my way of doing something about it."

The deaths of Janice in 2018 at age 65 and Karen in 2019 at age 66 have only further empowered the family to fight back against Alzheimer's. The Sitty's Angels team has continued participating in Walk year after year, growing to include over 75 people.

From 2017 to 2020, Kimberly volunteered as the Event Chair of the Heart of Alabama Walk to End Alzheimer's, and in 2021 joined the Association's Alabama Chapter Board of Directors. She is also an active advocate for Alzheimer's legislation at the state and federal levels and recently volunteered as an Alzheimer's Association Ambassador to Sen. Tommy Tuberville (R-Ala.).

Kimberly has also made generous annual donations to the Association through the Zyne Family Foundation, a charitable fund where she serves as executive director. She hopes the donations

and her volunteer efforts help increase concern and awareness of Alzheimer's and bring the disease into the spotlight.

"Every time I'm at an event table representing the Association, people come up and whisper, 'I think this is happening to my mom, but we don't know what to do,'" she says. "And they are whispering because it is not talked about."

According to Kimberly, people facing the disease need to know that help is available through the Association. The resources and sense of community the Association offers provide Kimberly's family a feeling of solidarity and the understanding that they are not alone in facing the disease.

"Every dollar counts. And I know these dollars go toward a mission of moving things forward and making real change," Kimberly says. "Donating and volunteering can be your way of fighting for people like my mom, giving them a voice." 98