'Cancer of the soul' robs Flower Mound family of wife, mother

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Alex Brown, 15, stands with her arms crossed. Her mouth is stiff and her eyes are fixed on the floor. Her stance is one of typical adolescent distress. But her pain is much deeper.

She and her brothers are visiting their mother, Michelle, at an Alzheimer's and dementia facility in Flower Mound. Alex hates it there, hates seeing the stranger in her mom's body.

MELANIE BURFORD/DMN
Bill Brown consoles daughter Alex, 15, who is distraught over the decline of her mother, Michelle Brown (right). Nanny Heather McLendon was with the family at Autumn Leaves care facility.
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The kids don't like it in her room, so Michelle's husband, Bill, escorts her into the hallway. She shuffles out, her fingers in her mouth. You can tell she had Alex's face once upon a time, before the life left her eyes.

Wes, 18, mumbles a subdued, "Hi, Mom." Harrison, 10, gives a more enthusiastic greeting. He's too young to remember when things were different. Normal.

"Hey, Mom!" Harrison says, smiling.

Michelle jumps up and down, her clenched fists moving in circles by her sides, as though she is holding a pretend jump rope. She lets out two high-pitched yelps. Alex begins to cry.

Physically, Michelle is still here. But her family lost her years ago.

It has been three years since Michelle, 49, was found to have frontotemporal dementia, a disease that destroys the brain lobes that control social skills, abstract thinking and language.

Those who have watched loved ones suffer from the disease refer to it as "cancer of the soul." People who have it usually remain physically healthy until the illness's end stages, but mentally they are transformed. They begin acting childlike, socially inappropriate and distant. Many patients seem devoid of emotion. Eventually, they are unrecognizable.

The disease commonly affects people between the ages of 40 and 65, says Susan Dickinson, executive director of the Association for Frontotemporal Dementias. She says that about 250,000 people in the United States are afflicted by such illnesses but that many more cases go undiagnosed or are misdiagnosed as psychological disorders.

The disease has no known causes, says Dickinson. Some cases appear to have a genetic link, but others, like Michelle's, appear to strike at random.

The time between diagnosis and death ranges from two to 15 years.

The illness leaves families in an emotional limbo, stuck grieving for a person they haven't entirely lost. Which is where the Browns find themselves today.

'She was just beautiful'

Michelle, who was born in Florence, S.C., was a true Southern belle. Her clothes and hair were always immaculate, "even if she was going out to rake the leaves," says her father, Jack Hodges, who lives in North Myrtle Beach, S.C. Her mother, Betty Anne Buchanan of Ninety Six, S.C., says Michelle was "the brain in the family."

Michelle graduated from Lander University in Greenwood, S.C., with a degree in business. Her husband remembers seeing her for the first time in 1989, at a party in Charlotte, N.C.

"She was just beautiful," says Bill, an account director with DDB New York, an advertising agency. "She seemed smart, and very shy."

Bill made his way past the crowd of men surrounding her and introduced himself. Five months later, he and Michelle got engaged.

Throughout their marriage, Michelle was successful in the health care industry. When Bill's job landed them in Flower Mound eight years ago, Michelle decided to be a stay-at-home mom to their three children.

She would read to Harrison's classroom, give Alex cooking lessons, and go to Wes' hockey games. As Michelle's oldest, Wes has the most vivid memories of his mom. He says she would press him to work hard.

"During every school break, she'd give me a big book of math problems," he remembers. "She gave me money, maybe a quarter, if I did one page.

"I guess she was just really involved."

Problems

In 2002, things began to unravel. She stopped throwing dinner parties, Bill says, and started holing up in her room, reading romance novels.

Ashley Osborne, Michelle's half-sister, who lives in Plano, recalls being dumbfounded by Michelle's behavior after Osborne's ex-husband died unexpectedly in 2004 of complications related to diabetes. At his wake, Michelle touched him, and with genuine curiosity said: "He's so stiff. How do you think he got so stiff? What did they put in him?"

Before Thanksgiving in 2005, an 11-year-old Alex approached her father and said, "I can't remember the last time Mom hugged me or kissed me, or told me that she loved me." When Bill relayed this to Michelle, she brushed it off and said, "I'll get to it."

After a misdiagnosis of depression, a June 2006 doctor's visit revealed the real problem. On the way home, Bill clutched the steering wheel as he sobbed. Michelle stared ahead, emotionless.

Later that year, the impeccably dressed woman who had once shopped at Ann Taylor had a daily uniform of blue jeans and a bathrobe. In the summer heat, she would circle the neighborhood, rummaging through the neighbors' trash.

In August 2007, Bill moved Michelle into Autumn Leaves, an Alzheimer's and dementia facility. She stands out next to the other 43 residents. In addition to being much younger than they are, her symptoms also are different. She recognizes her family and even remembers her library card number, but acts out in various ways. She will try to sneak sweets and junk food when no one is looking and will throw temper tantrums when she gets frustrated.

She does not communicate verbally much anymore. But Jodie Massey, community relations director at the facility, says it's clear that she knows her family. When she sees Bill, "she just lights up," she says.

Trying to move on

Alex and Wes distract themselves with school, sports and social activities. They sit by while their friends complain about run-of-the-mill teenage problems. School. Boyfriends and girlfriends. Moms.

"I always hang out with them so I don't have to think about it," Alex says. "So I can feel like just a normal teenager."

As the oldest, Wes has quickly had to become an adult. He looks after his siblings and acts as a sounding board for his father.

"Sometimes my dad talks about things I don't necessarily want to hear about, things maybe he used to talk to my mom about," he says. "He relies on me a lot."

Wes listens while he discusses work matters, and acts as an intermediary between his father and sister.

"My dad doesn't really get my sister sometimes," he says. "Sometimes he doesn't think stuff will bother her, but she's a girl, so it bothers her. Then she's just kind of quiet and won't tell him, so I will."

The kids used to visit their mother every weekend, but their trips have become less frequent.

"To me, it's like she's already passed away," Alex says. "This is dragging on. I know it's horrible to say, but it would just be easier if she died. I just don't want her being like this. It's unfair to her."

The disease's slow progression and unpredictability are also taking a financial toll on the family. Bill recently learned that Michelle would no longer qualify for hospice, which had been providing medical supplies for free since May.

"She gained weight and got some of her color back, so they said she probably wouldn't die within six months," said Bill, who will now need to spend about $300 a month on those supplies. "With Weston's college expenses, Alex's car insurance and Harrison's monthly orthodontic bill, I'm ready to explode."

Bill misses the woman he fell in love with 20 years ago. The woman who had never driven in the snow but gladly picked up and moved to Denver when Bill was relocated, before they moved to Flower Mound. She brought structure to the family, he says, and is 100 percent responsible for the kids' nearly perfect grades in school.

"I had a partner for so many years, and then, it's tragic; one day you just look, and they're gone," Bill says. "But she would want these kids to have a future. She'd want that for all of us. We have to evolve as a family."

Osborne, Michelle's half-sister whose ex-husband's diabetes was compounded by alcoholism, says her niece and nephews are experiencing a very different loss than her four children endured.

"We went through hell for several years," Osborne says. "But I almost think that what my kids went through was much easier, because they can move on quicker. It's almost like your life gets put on hold."

The Browns are making piecemeal efforts to move on. Bill, who sits on the board of the Association for Frontotemporal Dementias and is chairman of its advocacy committee, recently refurbished Harrison's room – Michelle's youngest had outgrown the cowboy-themed decorations she picked out before getting sick. Wes is attending Austin Community College. Alex talks to their nanny when she has problems and wants a woman's perspective.

In August, the Browns had their first family portrait taken without Michelle.

Bill still visits her every day when he isn't out of town on business. And sometimes, he finds himself rewinding time, trying to pinpoint exactly when she got sick.

"I'll go back and look at pictures, and I'll look at her eyes and try to figure out if she had it then or not," he says.

These days, Michelle's activities consist of disease-induced behavior and remnants of who she used to be. She'll drift in and out of naps and wander aimlessly down the halls of Autumn Leaves. But sometimes she will use the facility's computers, almost always ending up at the Web site of the Flower Mound Public Library, where she used to volunteer. Autumn Leaves staff members say she can also be found dancing to the more upbeat melodies played on Country Music Television.

Bill wants to minimize his children's pain in any way he can, so he doesn't force them to visit. When he talks about Michelle's absence in their lives, he tears up.

"It's a horrible existence for her and painful for the kids to see her this way," he says. "I just want this to be over."

Harrison visits the most out of the three children. For Mother's Day, he wrote a poem for his mom titled "Michelle."

"Loving, nice, caring daughter of Jack Hodges and Betty Anne," he wrote. "Lover of '80s music, who feels happy when loved. Who needs love."

The last line of the poem reads, "Who would like to be her normal life."

AT A GLANCE

THE DISEASE

Frontotemporal dementia affects about 250,000 Americans a year.

Victims commonly are between the ages of 40 and 65. It is similar to Alzheimer's disease in that it involves a gradual, progressive loss of brain function. But where Alzheimer's affects memory, frontal lobe dementia strikes at behavior and language function.

SYMPTOMS

Symptoms include speech difficulties, repetitive compulsive tendencies, socially inappropriate behavior, loss of empathy, sudden aversion to personal hygiene and movement abnormalities, such as tremors.

INFORMATION

The Association for Frontotemporal Dementias operates a help line at 866-507-7222, or visit their Web site at **www.ftd-picks.org**.

SOURCE: Association for Frontotemporal Dementias