

HOME & DIGITAL

Finishing the Work of a Mother With Alzheimer's

A daughter takes on completing her mom's book as dementia sets in

By CLARE ANSBERRY

Dorothy Hampton Marcus was diagnosed with Alzheimer's when her memoir was half-finished. She had been working on the book for about a decade, hoping to leave a record of her life growing up in the South during the Jim Crow era, working as a civil rights activist, secretly dating and then marrying a prominent black preacher.

As the disease progressed and it became clear she couldn't finish, her daughter Kaypri took over, completing the book, "I Didn't Know

What I Didn't Know: A Southern White Woman's Story About Race," in time for her mother's 80th birthday in 2012.

"I never would have forgiven myself if I didn't finish it. It was too important to her," says Kaypri, who goes by that name only. It proved invaluable to Kaypri as well. In completing the self-published memoir, she says she came to more fully appreciate her mother's achievements, as well as her insecurities.

An estimated 5.4 million Americans—one in nine people age 65 and older—have Alzheimer's disease. As it progresses, it destroys memory and other brain functions. Families are left with unfinished business that can involve finances, relationships or projects. Meryl Comer said her husband, a scientist who was diagnosed with early-onset Alzheimer's, didn't pay taxes for four years. It wasn't that he deliberately ignored them. "It's the disease that creeps over them. They lose control," says Ms. Comer, co-founder of Women Against Alzheimer's and author of "Slow Dancing with a Stranger," a book about the couple's 20-year battle with Alzheimer's.

Alzheimer's symptoms can start two years before an official diagnosis and during that time problems can go largely unnoticed, especially if the person lives far from family.

Children and spouses have little choice but to pay bills and clean out homes. But they often feel compelled to finish something that seems incidental but was particularly meaningful to a parent or loved one, says Ruth Drew, director of family and information services for the Alzheimer's Association. Restoring a car or a rose garden can be a way to honor a parent and can also provide closure. Completing an unfinished project can help family members feel as if they are putting pieces of their own shattered lives back to-



Dorothy Hampton Marcus and her daughter Kaypri, above, with the finished book. Top right, Kaypri, center, with her parents. Right, Ms. Marcus's civil-rights work was covered in a local paper in 1967.



gether. "It can be part of their healing process," she says. Ms. Marcus, the youngest of six children, was born in 1932 in Winston-Salem, N.C. Like many other families at that time and place, they had an African-American cook. "I'm sure we thought we were good to them because we gave them leftover food and outgrown clothes," she wrote.

While attending an all-white Southern Baptist women's college in the 1950s, she became involved in a then-radical experiment, hosting exchanges with students from an African-American college across town to talk about race and attending a National Negro Student Convention. She taught Sunday school at a black church and worked at an interracial camp in New Hampshire.

Some family members didn't approve of her work, but her parents backed her, opening their home when she invited both black and white friends to a party. She remembers her father welcoming guests and reaching out to shake the hand of an African-American man for the first time in her memory. "I was only beginning to challenge the rigid segregation that I had been raised in," she wrote.

After graduating, she began a career as a civil-rights activist, working in Raleigh to help desegregate churches, in Michigan to mediate between black groups and city officials before and after the Detroit riots, and in Philadelphia

to integrate neighborhoods. Along the way, she kept newspaper articles, and journals, recording observations and conversations.

In the course of her work, she met Chester Marcus, an African-American preacher and widower with a young son. They dated secretly for more than a decade, meeting at conferences, before marrying in 1972 and moving to Teaneck, N.J. She was 40, and he was in his mid-50s. Her brothers refused to come to the wedding and cut ties with her. Two sisters came.

'A lot of times, I'll read things and it feels like the first time I've ever seen them,' she wrote.

A year later, her first and only child, Kaypri, was born. Ms. Marcus quit working to take care of her daughter but continued to do community work and consult on race relations. Mr. Marcus traveled often, spending months at a time in Africa. He suffered a major stroke when Kaypri was in fourth grade and died seven years later.

It took Ms. Marcus a long time to begin her book because she was busy and because she didn't think she had anything worth saying. She played down her contributions, saying she never felt she was part of the civil-rights move-

ment because she didn't march in Washington or Selma. Friends, her daughter and a therapist convinced her otherwise.

She began taking writing classes at the 92nd Street Y in New York City and organized a group of writers at Riverside Church in Harlem. She read memoirs, biographies, autobiographies, and histories of the civil-rights movement, and pored over her journals. "I slowly came to realize that my story really was unique and that I just never considered this fact the entire time I was living it," she wrote.

Ms. Marcus started writing in her late 60s, emailing occasional chapters to Kaypri, who lived in California, and discussing progress over the phone. A few years later, her emails started becoming more disjointed and depressed. On a visit to her mother, Kaypri saw mail and newspapers all over the apartment. A doctor confirmed her mother had Alzheimer's. When it became too hard to manage her care from a distance, Kaypri moved her to California in 2011.

By then, about half of the book was done. Some chapters had six versions. Ms. Marcus's writing became increasingly jumbled, and she didn't recognize her own words. "A lot of times, I'll read things and it feels like the first time I've ever seen them. That bothers me," she wrote.

Kaypri says she realized she had to finish it and began inter-

viewing family and those who worked with her mom. Writing came naturally to Kaypri, an actor, writer and producer who has written plays and screenplays. But the task wasn't easy.

Some passages in her mother's journals, especially about her parents' marriage, were painful. Her father traveled often and when he got home, he wanted to stay home, while her mother wanted to go out with him. "In our entire marriage, we never went out to eat once or even went to a movie. I realize this is my fault for not speaking up and forcing his hand, but at the time I was caught up in a codependent, catering role, trying to make sure he was happy the short times he was home and my needs came last," her mother wrote.

Kaypri says that saddened her. "Both my parents were passionate about making things better, but it wasn't a true love story and that's sad," she says.

Kaypri rushed to finish a draft of the book in time for her mother's 80th birthday in 2012. She started selling the 284-page book on Amazon.com in 2014.

Now 84, Ms. Marcus can no longer talk, walk, feed or dress herself, but she recognizes her daughter. Kaypri says she often places the book in her mother's hands and points to the photos, describing who is in each one. "It was the hardest thing I have ever done, but the most important," she says.