

Never Giving Up & Never Wanting To: A Caregiver's Journey

Barry Tutor

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Barry Tutor probably never expected to find himself the sole caregiver for two loved ones with Alzheimer's disease (AD). When his elderly mother and, later, his middle-aged wife were diagnosed with AD, Tutor stepped up to the challenge. *Never Giving Up & Never Wanting To* is based on his experiences as a caregiver. Sharing the details of his struggle to care for his mother and wife as they face the ravages of their disease, he provides an insider's perspective that is chilling, informative, and touching.

Tutor is unwaveringly frank, and he writes clearly and well, whether speaking of his undying love for his wife, discussing the need for Alzheimer's education, or expounding on his theories about the federal government's role in Alzheimer's research and treatment. Not one to mince words, he states from the beginning that "caring for someone with Alzheimer's disease ... will rule and possibly ruin your life." Tutor's book is an eye-opener.

For those with little knowledge of the disease, Tutor quotes from the Alzheimer's Association's website (www.alz.org), providing basic outlines of signs and stages of AD; he also includes a list of additional websites that provide helpful information. For caregivers, Tutor offers in-depth suggestions and tips, all gathered in the course of the author's own journey.

While the information he provides is educational, it is not what stands out most in Tutor's book. Tutor is a tenacious and dedicated advocate who refuses to give up on his loved ones, and it is his determination to humanize not only his wife and mother but also other victims of AD that gives the story its depth. He mentions heartbreaking slights and indifference on the part of everyone from neighbors and friends to family members, illustrating the isolation that envelops both Alzheimer's patients and those close to them. Tutor is, by his own admission, sometimes sarcastic, displaying "strong opinions and deep hatred" and expressing disappointment in others who fail to come through for his family.

Never Giving Up & Never Wanting To provides invaluable information, assistance, encouragement, and even empathetic comfort to anyone close to an AD patient. It is not an easy book to read, though, because Tutor sugarcoats nothing. He is usually able to check himself when he begins to sound too sour or annoyed, and he does seem to go out of his way to avoid displaying self-pity.

His is a story of commitment, not hope, and his admonitions to always "be prepared for the worst" are a constant reminder that things will never get better. Between the sadness and the frustration, the devastation and the sacrifices, Tutor, too, is suffering, and his pain is obvious. Only someone with firsthand experience could display so much compassion, and, at the same time, show so clearly that Alzheimer's victims are not limited to those diagnosed with the disease.

CHERYL HIBBARD (March 29, 2013)

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