

## Remembering the Forgotten: A Look at Alzheimer's disease

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Sue Miller's *The Story of My Father* is an astonishing and moving memoir about the struggles of caring for a parent with Alzheimer's disease. Miller is an immensely eloquent writer who has tackled a wide variety of issues in her previous novels, but this gripping personal tale of her desperation and struggle of dealing with the life and death of her father is a definite page-turner. I found myself immersed within the life of Sue Miller; I experienced with her that first look of non-recognition in her father's eyes as he looked at her from inside a police station. The states of confusion and disorientation that followed were every bit as real for me to read as they were for her to write.

As we age, we are often faced with the gripping reality that we will eventually lose our minds, but what does it mean to become the caregiver of someone in that position? Miller takes us on an intense personal journey as she herself tries to understand the disease that has crippled the memories and life of her father. Miller delivers a descriptive retelling of the morning she found herself awoken by a phone call from the police: Her father, James Nichols, had been found wandering through the night in western Massachusetts with no memory of how he had gotten there. When she arrived to pick him up, the image of her father unshaven and wearing old clothes – a look of someone lost, belonging nowhere – ironically serves as foreshadowing of the revelation of his disease to come. Miller could not then have imagined the emotional journey she would begin over the next five years and that would continue beyond her father's death.

Labeled as the 'dread disease of our time', Alzheimer's disease – coined by founding father Alois Alzheimer in 1907 – was first seen as abnormal clumps and tangles of fibers where brain cells should have been seen. Later documentation explained that Alzheimer's was a gradual disease that begins with forgetfulness and gradually progresses to severe memory loss as well as problems with thinking and behavior severe enough to affect work, lifelong hobbies or social life. As many as 5.3 million Americans live with Alzheimer's disease, which is also the fourth leading cause of death among Americans. There is no cure for the disease, which can only be officially diagnosed after death through autopsy. The diagnosis for current patients, however, is probable Alzheimer's disease. Still, Miller feels a sense of relief when she can put a name to the illness and finally explain her father's strange behavior that ranges from general confusion to seeing things that aren't actually there.

The book gives a full picture of the subject of Alzheimer's from both sides of the disease: The people with the disease and those who care for them. As Miller aims to cover timely and important developments regarding the terrible course of Alzheimer's disease, I found myself mystified by it all. Not only do those with Alzheimer's deal with the reality that day by day they are losing pieces of themselves, but they must also readjust each day to the frustration and agitation that comes with experiencing what should be a familiar place instead as a place of novelty and strangeness. The question that arises is 'Why does this still work, and not that?' Difficulties also lie in knowing that something is wrong but not understanding the implications of it all. Miller's father gets frustrated by his inability to say exactly what he wants, and then he grows more and more

agitated. For many Alzheimer's patients, the paranoia and profound memory impairment that come with the disease affect their job performance as well as cause difficulties performing everyday tasks; disorientation in time and place; poor judgment; and problems with language, like forgetting words. Though often bewildered, Miller imparts breathtaking clarity through the recollections of her father's history and life. Her father had once led a strong and productive life as an ordained minister and professor of church history. Now, his life, once filled with purpose and meaning, has been replaced only with hallucinations, agitation, and occasional violence. Miller eventually comes to the realization that no matter what she did for her father, he would only get worse as his disease progressed. Miller explains, "My particular version of the caregiver's dilemma, then, was one of confusion: moral confusion, emotional confusion, ethical confusion, practical confusion." People often say patients die from Alzheimer's, but in actuality it is not strictly the disease that kills patients. Rather, death happens because they have succumbed to the things that come with having Alzheimer's. Some may die of starvation because they've forgotten how to eat, while others die from things like urinary tract infections. By the time Miller's father had his own version of death by Alzheimer's, he was extremely violent and was completely out of touch with reality.

The book flounders at some parts in its structure as Miller devotes pages to her family history, even more space to Alzheimer's research, and still more to her own struggles with the grief and anguish of watching her father die. However, the book delivers its readers into the personal nature of her story with a sort of quintessential vibrancy. Miller perceptively presents the shifting relationship between parent and child. When the parent suddenly becomes dependent on the child, the relationship ends up full of unique tensions and aggravations that many of Miller's readers can relate to.

The part of the book that I deeply enjoyed most was Sue Miller's afterword, in which she explains what it was like to write this memoir. In a sense, the afterword acts as a bit of a consolation for those readers in the same situation Miller faced; with this consoling tone, Miller appears to draw her readers closer to her experience in the afterword than in the actual memoir. *The Story of My Father* approaches its end with an interview of Miller as she yet again takes us through her experiences surrounding her father's illness and death. She credits her writing of this memoir to the prolonged grief she felt over losing her father. Miller began writing with the feeling that the book was a sort of consolation for her and her father. However, through her research for this book, she realized that the one thing that stayed with her father even after he slipped into oblivion was his faith, and that this memoir would not have mattered to him. Miller explains, "[F]or him life and death already made sense." The book comes to a final end with questions for discussion about themes of the social, emotional, ethical and scientific implications of her memoir. As such, Miller's moving memoir is a good read for stirring up your next book club!