

Book Review: Speaking Our Minds

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BOOKSHELF

The Last Childhood

By Judith L. DuSell

***The Last Childhood,*
by Carrie Knowles
(Three Rivers Press 1997)**

As time progresses and the baby boomers get older, attorneys who practice elder law will have to face the difficulties of clients with Alzheimer's disease. These persons will most likely be presented to attorneys by caregivers, probably a family member or friend who is concerned about the elder person's physical and financial well being. While attorneys must handle their clients, the persons afflicted with Alzheimer's, it is inevitable that they also may need to address the concerns of the caregivers.

The Last Childhood is the story of a family who is confronted with the devastating effects of Alzheimer's disease. It is the personal tale of the author, Carrie Knowles, and her siblings, who are thrown into the strange world of caregivers, when it is determined that their mother is exhibiting signs of Alzheimer's disease. The reader is taken through the experiences of the Knowles family as they progress from the early stages to the more critical, and often more difficult, stages.

The reader experiences the family's struggle as the mother fades in and out of periods of lucidity. The author's mother was remembered as kind and loving, a constant companion to their blind father on his various travels with Leader Dogs, a guide-dog agency. Unfortunately, while her mother was still physically well, her mental state began to decline, and she exhibited strange behaviors and tendencies. In the early stages, the mother behaved irrationally, even accusing her children of attempting to kidnap and poison her. At the same time, it became more evident that she would be unable to care for herself as her financial matters were disorganized, and her own health and safety seemed at risk. The terrible nature of Alzheimer's disease is a long and decomposing process. The Knowles family had to slowly acknowledge their mother's illness as she began to forget her children's names and did not recognize her own home or those of her family.

The reader is also taken along for the Knowles family's sad journey as they can no longer care for their mother and must place her in a nursing home. The siblings

all struggle to understand their mother's need for a doll, which she cares for as a real child, at the same time as they discuss the difficult decisions that must be made with regard to life-sustaining treatment and medications. Interesting battles occur between the family and medical practitioners concerning the ability to provide their mother with sweets as well as gifts at Christmas time. The book shows the efforts of the family to maintain their own sanity and remember the "normal" times with their mother.

While this is a personal story, *The Last Childhood* is reflective of the struggles of all Alzheimer's caregivers. When people are informed that a loved one is afflicted with this disease, it can have overwhelming effect on a family. Many children of Alzheimer's patients feel greatly uncertain when

their loved one goes from "Mom" or "Dad" to a more childlike state. The parents, who were once admired for being caregivers themselves, are now perceived as dependent and detached. It is a difficult and trying situation to accept.

While it is deeply emotional, the story of *The Last Childhood* is an accurate tale of the trials of a caregiver. Carrie Knowles expresses the fears and doubts that families have concerning the health and financial well being of the afflicted, as well as the sanity and stability of the family who remain in the lucid world. She poignantly describes the pain that family members feel when their loved one is skirting in and out of the real world during the early stages, as well as the hopelessness they feel in the later stages.

This book is highly recommended for those who have a family member with Alzheimer's disease. If not to understand that they are not alone in their struggles, it should be read to better understand how the situation might evolve. While not every Alzheimer's patient and family will go through the same struggles as the Knowles family, the author provides clues and ways that early recognition may be possible as well as coping skills for the family. An attorney assisting a client with Alzheimer's disease with financial planning and probate issues may be in a good position to provide some guidance and strength for the caregiver as well. Carrie Knowles' book, *The Last Childhood*, helps ease the pain of the Alzheimer's caregiver and prepares them for the long battle that lies ahead.

BOOKSHELF

Speaking Our Minds

By Beth Ellingson

***Speaking Our Minds: Personal Reflections from Individuals with Alzheimer's*, by Lisa Snyder, LSDW (W.H. Freeman and Company 1999)**

Lisa Snyder is a clinical social worker at the University of California, San Francisco's Alzheimer's Disease Research Center. In the early 1990s, when Alzheimer's symptoms were beginning to be diagnosed in the earlier stages, Ms. Snyder embarked on a study of several patients that had been diagnosed, but had not yet lost their ability to speak. Her goal was to record their reactions, feelings, and ways of coping with the insidious onset of this disease. She interviewed seven unique patients and gained insight into some of their most private emotions, as well as learning about her own judgments about people with Alzheimer's.

The book is divided into ten sections. The first two sections outline the methods Ms. Snyder used to compile the results of her interviews, as well as helpful definitions of frequently used terms in the book. The remainder of this piece, however, has little to do

with the clinical aspects of Alzheimer's Disease. Instead, *Speaking Our Minds* reveals compelling profiles of seven of the disease's victims.

The first patient described in the book is Bea, a seventy-two-year-old, cheerfully pleasant woman that is twice widowed and now in her third marriage. Bea recounts a few very small incidents that raised her suspicion enough to be seen by a doctor. She talks of seeing several health care professionals, none of whom had any empathy for her feelings when she was diagnosed. Throughout this work, all of the patients interviewed report a lack of understanding and compassion from not only health care professionals, but from the general public as well. After her diagnosis, Bea was unable to do even the simplest tasks, and expressed fears of leaving her home. Nearly all of the patients that spoke with Ms. Snyder expressed fears of "forgetting" where they were, and shame when they need to ask for help.

Another common theme introduced in Bea's story is the toll that providing care for an Alzheimer's-stricken family member can have on the care-giver.

She describes, at some length, the frustration that her husband, Jim, experiences as her primary caregiver. Bea and Jim have learned how to cope by finding humor in difficult situations. However, Bea and the other Alzheimer's patients portrayed in *Speaking Our Minds* express regret because they have become a burden to their loved ones.

Nowhere in this book is the toll taken on the family of an Alzheimer's patient better described than in the case of Bill. Bill is a husband and father of two, working as a foreign correspondent when he is diagnosed. Bill is only fifty-four, and is devastated by the disease. The loss of his ability to spell, then the loss of his ability to write altogether are sources of great frustration for him. He tells a story of finally disconnecting his computer because he can no longer remember how to operate it. He also explains that his loss causes him a great deal of anger. As many Alzheimer's

patients do, Bill often wonders, "Why me?" Bill now depends on his wife to help him with even the smallest tasks. Yet despite the anguish the early onset of Alzheimer's has caused, Bill is able to find joy in becoming child-like. He takes interest in the daily, small things he experiences, such as a morning walk. As the other patients in Ms. Snyder's study, Bill still expresses hope that a cure may be discovered for Alzheimer's. The author discusses hope as another common coping mechanism, at the same time cautioning patients who might place their hopes in untested alternative remedies.

The stories of Bea, Bill, and the other Alzheimer's patients portrayed in *Speaking our Minds* allow readers to better understand what this disease means to its victims, caregivers, and even strangers. Ms. Snyder deftly illustrates the frustration, depression, and fears that plague Alzheimer's patients. Certainly this would be enough to give readers an under-

standing of the disease's effects. However, the book goes further in revealing the unique coping strategies employed by Alzheimer's patients and their caregivers. Through Ms. Snyder's perspective, the reader can also explore whether or not his or her own perceptions of Alzheimer's disease are accurate.

Speaking Our Minds is highly recommended for the practitioner who wishes to explore beyond the clinical aspects of Alzheimer's disease to get an understanding of the disease's effect on the emotions of its victims and their caregivers. Despite the book's size (only 160 pages), any reader can come away with a greatly expanded awareness of what it means to have Alzheimer's disease. In addition, practitioners may wish to recommend Ms. Snyder's book to clients with Alzheimer's and/or their caregivers to help them appreciate the power of the disease, as well as suggest coping strategies to persevere through difficult times.