

Still Alice

by Lisa Genova

About the Book

She didn't want to become someone people avoided and feared. She wanted to live to hold Anna's baby and know it was her grandchild. She wanted to see Lydia act in something she was proud of. She wanted to see Tom fall in love. She wanted to read every book she could before she could no longer read.

Alice Howland is proud of the life she has worked so hard to build. A Harvard professor, she has a successful husband and three grown children. When Alice begins to grow forgetful at first she just dismisses it, but when she gets lost in her own neighbourhood she realises that something is terribly wrong. Alice finds herself in the rapid downward spiral of Alzheimer's disease. She is only 50 years old.

While Alice once placed her worth and identity in her celebrated and respected academic life, now she must re-evaluate her relationship with her husband, her expectations of her children and her ideas about herself and her place in the world.

Losing her yesterdays, her short-term memory hanging on by a couple of frayed threads, she is living in the moment, living for each day. But she is still Alice.

Still Alice is as compelling as *A Beautiful Mind* and as powerful as *Ordinary People*. You will gain an understanding of those affected by early-onset Alzheimer's and remain moved and inspired long after you have put it down.

Praise for the Book

“A poignant portrait of Alzheimer’s...Not a book you will forget.”

—*USA Today*

“After I read *Still Alice*, I wanted to stand up and tell a train full of strangers, ‘You have to get this book.’...I couldn’t put it down...*Still Alice* is written not from the outside looking in, but from the inside looking out...[It] isn’t only about dementia. It’s about Alice a woman beloved by her family and respected by her colleagues, who in the end, is still Alice, not just her disease.”

—**Beverly Beckham, *The Boston Globe***

Courtesy of Simon & Schuster

About the Author

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Known As: Seufert, Lisa Genova; Genova, Lisa
American Novelist

Source: *Contemporary Authors Online*. Detroit: Gale, 2010. From *Literature Resource Center*.

Document Type: Biography

Full Text: COPYRIGHT 2011 Gale, Cengage Learning

Updated:03/25/2010

PERSONAL INFORMATION:

Children: one son, one daughter. Education: Bates College, B.S.; Harvard University, Ph.D.

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CAREER:

Writer, actor, research scientist. National Alzheimer's Association, online columnist; has performed various scientific research pertaining to molecular etiology of depression, Parkinson's disease, drug addiction, and memory loss following stroke. Also performs on stage and in independent films.

WRITINGS:

- *Still Alice*, Pocket Books (New York, NY), 2008.

Contributor to the National Alzheimer's Association Web site.

'Sidelights'

Lisa Genova studied biopsychology at Bates College, where she earned a bachelor of science degree and graduated as valedictorian. She later attended Harvard University from which she earned a doctorate in neuroscience. Her scientific research interests cover a number of topics, including the molecular etiology of depression, Parkinson's disease, drug addiction, and memory loss in the wake of a stroke. Genova belongs to both the Dementia Advocacy & Support Network International and to DementiaUSA. In addition, she writes a regular column for the National Alzheimer's Association Web site. Outside of her scientific efforts, Genova is also interested in the arts. She performs regularly on stage, primarily in Boston, Massachusetts, and has acted in a number of independent films. Her debut novel, *Still Alice*, was published in 2008.

In *Still Alice*, Genova merges her scientific curiosity regarding Alzheimer's disease with the horror she felt when her beloved grandmother succumbed to the illness in her mid-eighties. When her grandmother was first diagnosed with the disease, Genova began to research the

illness, learning as much as she could about what was taking place inside her grandmother's brain. Much of the scientific material she studied discussed the molecular results of the disease's progress. Beyond that, however, she read more personal nonfiction accounts of living with Alzheimer's, much of which was written either by caregivers or clinicians analyzing the illness. Ultimately, however, her grandmother was too far along in the progression of the disease to tell Genova what she most wanted to know, which was how it actually felt to suffer from Alzheimer's. That burning question and Genova's search for an answer served as the origin for the novel. Genova tells the story of Alice Howland, a professor at Harvard University and a high-achiever, who begins to suffer symptoms of Alzheimer's and gradually, over a two-year period, is ravaged by the illness. Genova depicts Alice as a much younger Alzheimer's patient than is typical, having her first begin her decline at the age of forty-nine. This choice serves to show the extremes of the disease, including how it can rob a person of their livelihood, well-being, and self-respect, all within a short period of time. A reviewer for *Publishers Weekly* declared that "it's impossible not to feel for Alice and her loved ones, but Genova's prose style is clumsy." However, a contributor to *Kirkus Reviews* found the book "worthy, benign, and readable, but not always lifelike." Joanna M. Burkhardt, in a review for *Library Journal*, dubbed Genova's effort "realistic and compelling."

FURTHER READINGS ABOUT THE AUTHOR:

PERIODICALS

- *Kirkus Reviews*, November 1, 2008, review of *Still Alice*.
- *Library Journal*, May 1, 2009, Joanna M. Burkhardt, review of *Still Alice*, p. 50.
- *MBR Bookwatch*, May 1, 2008, Mary Cowper, review of *Still Alice*.
- *Publishers Weekly*, October 20, 2008, review of *Still Alice*, p. 31.

ONLINE

- *Lisa Genova Home Page*, <http://www.lisagenova.com> (July 18, 2009).*

Source Citation

"Lisa Genova." *Contemporary Authors Online*. Detroit: Gale, 2010. *Literature Resource Center*. Web. 27 Jan. 2011.

Document URL

http://go.galegroup.com/ps/i.do?&id=GALE%7CH1000191839&v=2.1&u=lom_kentdl&it=r&p=LitRC&sw=w

Gale Document Number: GALE|H1000191839

Author Essay

Essay By Lisa Genova

I wrote *STILL ALICE* because I am a granddaughter and a neuroscientist.

Looking back, my eighty-five-year-old, widowed grandmother had been showing signs of dementia for years. But she was a smart and independent woman who never complained, and she navigated around her symptoms with great skill for some time. And her nine children, their spouses, and her grandchildren were all content to look the other way or to pass off her cognitive mistakes to normal aging.

Then we got the phone call. She'd walked to the bowling alley at four in the morning, insisting it was middle of the day, looking for her bowling team. It was quite literally the wake-up call that forced my family to look directly at her and what was going on.

With nothing we could actually do to alter the course of her disease, like spectators we all watched Alzheimer's systematically disassemble the woman that was my grandmother. I watched her study her own face in the mirror, not comprehending the old woman's face she saw. I watched her fuss over plastic baby dolls as if they were real babies. I watched her check the numbers outside her front door, 148, her street address, over and over in the space of minutes, trying to assure herself that she was in her own home. She forgot her name, where she lived, to remember to go to the bathroom when she needed to, who her children were, who I was.

As a granddaughter, I was heartbroken. But as a neuroscientist, I was fascinated and wanted to understand more about this disease. I read everything I could find in the scientific literature about the molecular causes of Alzheimer's, and I read many books written by clinicians and caregivers about how to care for someone with dementia. I learned a great deal. But I couldn't find a satisfying answer to the question that kept coming up for me as I watched my grandmother.

What does it FEEL like to have Alzheimer's?

This curious question, unanswerable by my Nana, was the seed for *STILL ALICE*.

I wanted to write an inspirational story that, although fictional, would be a truthful depiction of life with Alzheimer's from the very first hints of having it, from those very first "What's the word?" and "What did I come in here for?" to the more haunting and confused "If I can't remember who I am, am I still me?"

And I wanted to tell a different kind of Alzheimer's story. Alice is only fifty when she is diagnosed. Most of us think of elderly people like my grandmother when we imagine Alzheimer's, but in fact about ten percent of people with Alzheimer's are under the age of sixty-five when symptoms first surface.

I also wanted to tell this story from Alice's point of view. In doing so, I sit the reader right up

against her Alzheimer's. It should feel uncomfortably close at times. The reader should feel her confusions and frustrations and terror right along with her. And the reader should also feel her courage, her humor, her victories, and her love. This choice does force us to lose what's going on inside the thoughts of Alice's husband and the other characters, but we get in insider's perspective into the mind of someone slipping further and further into dementia. Most people without Alzheimer's never get to sit in that seat.

I did a lot of research to create *STILL ALICE*. I knew I'd never be able to capture everyone's experience with Alzheimer's, but I knew I could capture the essence of it if I did my homework. On the clinical side, I interviewed neurologists, general practice physicians, research scientists, a genetic counselor, and a social worker. And on the patient side, through the Dementia Advocacy and Support Network International, I came to know about two dozen people living with young onset dementia. They were my litmus test. They are the true experts who bravely revealed to me what it feels like to have Alzheimer's.

For readers who have or know someone with Alzheimer's, I think *STILL ALICE* offers reassurance, comfort, dignity, and hope. For readers with no personal connection to Alzheimer's, I think *STILL ALICE* is a moving story that works because it's about so much more than Alzheimer's. It's about identity, about living a life that matters, about family and what a crisis does to relationships.

Through Alice's story, I hope readers will gain a greater appreciation and sensitivity for what people with Alzheimer's and their families struggle through. I hope they will come to understand the importance and value of an early diagnosis, the current medications, and support groups. And I hope they will finish the book knowing that we are all more than what we say, what we do, and what we remember.

Courtesy of Simon & Schuster

Discussion Questions

1. When Alice becomes disoriented in Harvard Square, a place she's visited daily for twenty-five years, why doesn't she tell John? Is she too afraid to face a possible illness, worried about his possible reaction, or some other reason?
2. After first learning she has Alzheimer's disease, "the sound of her name penetrated her every cell and seemed to scatter her molecules beyond the boundaries of her own skin. She watched herself from the far corner of the room" (pg. 70). What do you think of Alice's reaction to the diagnosis? Why does she disassociate herself to the extent that she feels she's having an out-of-body experience?
3. Do you find irony in the fact that Alice, a Harvard professor and researcher, suffers from a disease that causes her brain to atrophy? Why do you think the author, Lisa Genova, chose this profession? How does her past academic success affect Alice's ability, and her family's, to cope with Alzheimer's?
4. "He refused to watch her take her medication. He could be mid-sentence, mid-conversation, but if she got out her plastic, days-of-the-week pill container, he left the room" (pg. 89). Is John's reaction understandable? What might be the significance of him frequently fiddling with his wedding ring when Alice's health is discussed?
5. When Alice's three children, Anna, Tom and Lydia, find out they can be tested for the genetic mutation that causes Alzheimer's, only Lydia decides she doesn't want to know. Why does she decline? Would you want to know if you had the gene?
6. Why is her mother's butterfly necklace so important to Alice? Is it only because she misses her mother? Does Alice feel a connection to butterflies beyond the necklace?
7. Alice decides she wants to spend her remaining time with her family and her books. Considering her devotion and passion for her work, why doesn't her research make the list of priorities? Does Alice most identify herself as a mother, wife, or scholar?
8. Were you surprised at Alice's plan to overdose on sleeping pills once her disease progressed to an advanced stage? Is this decision in character? Why does she make this difficult choice? If they found out, would her family approve?
9. As the symptoms worsen, Alice begins to feel like she's living in one of Lydia's plays: "(Interior of Doctor's Office. The neurologist left the room. The husband spun his ring. The woman hoped for a cure.)" (pg. 141). Is this thought process a sign of the disease, or does pretending it's not happening to her make it easier for Alice to deal with reality?
10. Do Alice's relationships with her children differ? Why does she read Lydia's diary? And does Lydia decide to attend college only to honor her mother?

11. Alice's mother and sister died when she was only a freshman in college, and yet Alice has to keep reminding herself they're not about to walk through the door. As the symptoms worsen, why does Alice think more about her mother and sister? Is it because her older memories are more accessible, is she thinking of happier times, or is she worried about her own mortality?

12. Alice and the members of her support group, Mary, Cathy, and Dan, all discuss how their reputations suffered prior to their diagnoses because people thought they were being difficult or possibly had substance abuse problems. Is preserving their legacies one of the biggest obstacles to people suffering from Alzheimer's disease? What examples are there of people still respecting Alice's wishes, and at what times is she ignored?

13. "One last sabbatical year together. She wouldn't trade that in for anything. Apparently, he would" (pg. 223). Why does John decide to keep working? Is it fair for him to seek the job in New York considering Alice probably won't know her whereabouts by the time they move? Is he correct when he tells the children she would not want him to sacrifice his work?

14. Why does Lisa Genova choose to end the novel with John reading that Amylix, the medicine that Alice was taking, failed to stabilize Alzheimer's patients? Why does this news cause John to cry?

15. Alice's doctor tells her, "You may not be the most reliable source of what's been going on" (pg. 54). Yet, Lisa Genova chose to tell the story from Alice's point of view. As Alice's disease worsens, her perceptions indeed get less reliable. Why would the author choose to stay in Alice's perspective? What do we gain, and what do we lose?

Enhance Your Book Club:

1. If you'd like to learn more about Alzheimer's or help those suffering from the disease, please visit www.actionalz.org or www.alz.org.

2. The Harvard University setting plays an important role in *Still Alice*. If you live in the Cambridge area, hold your meeting in one of the Harvard Square cafés. If not, you can take a virtual tour of the university at: <http://www.hno.harvard.edu/tour/guide.html>

3. In order to help her mother, Lydia makes a documentary of the Howlands' lives. Make one of your own family and then share the videos with the group.

4. To learn more about *Still Alice* or to get in touch with Lisa Genova, visit www.StillAlice.com.

Courtesy of Simon & Schuster