

## Still Alice

Author: Lisa Genova

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Dr. Alice Howland is a successful Harvard professor of cognitive neuroscience, at the head of the field in Linguistics. She is a mother of three grown children and the wife of a successful Harvard Biology professor. Due to a single amino acid mutation in a single gene, she also has early onset Alzheimer's disease (EOAD). This is the story of the Alice that was, and the Alice that will continue to be, even after her devastating diagnosis. Her heartbreakingly beautiful story follows her as she explores her sense of self, though few aspects of her personality are immune to the ravages of her disease, and what her place in the world will be when she no longer remembers the woman she was.

This work of fiction is the debut novel of Dr. Lisa Genova, who holds a PhD in Neuroscience from Harvard University. Having watched her own grandmother suffer from Alzheimer's disease, Genova wanted her book to convey the experience of those who suffer from this progressive neurodegenerative condition. The result of her efforts is a thoroughly researched story which has been well received by patients and general readers alike, winning the 2008 Bronte Prize for women's fiction. Genova delivers Alice's story in plain, unornamented, and sometimes even clinical style, which belies the strong emotions the book brings forth.

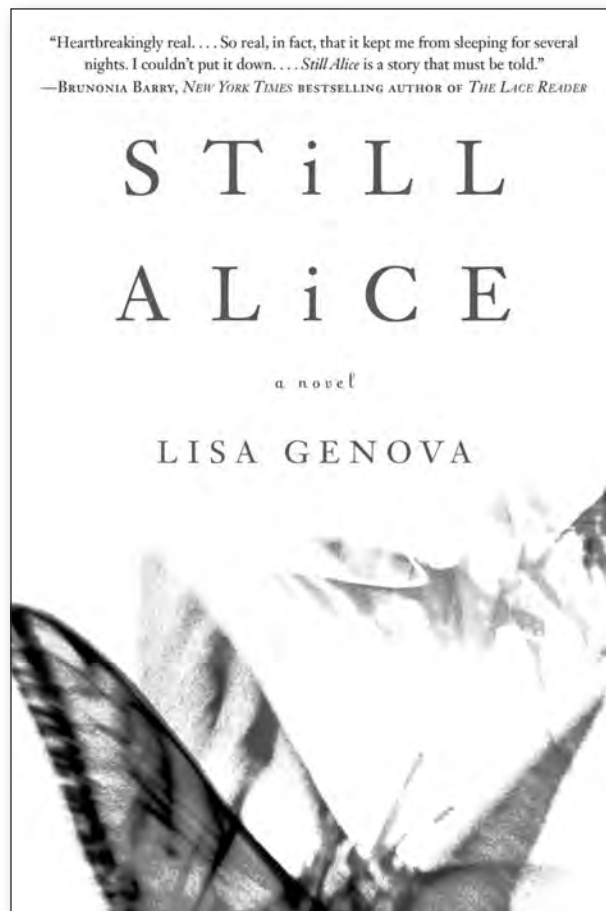
The book is written in third person narrative, with insight into only Alice's thoughts. This account confronts the reader with Alice's experience, as every scene is related through the lens of Alice's struggle with EOAD. As the story progresses in vignettes throughout two years of Alice's life, there are obvious changes in Alice's cognition and perception. There are good days and difficult days. The story moves you with Alice's moments of upset and despair, and on Alice's

behalf, in the moments when she cannot grasp the tragedy reflected in the eyes of her unrecognizable loved ones. Throughout the story the reader sees many glimpses of Alice; the polished professional invited to speak to a room of experts; the demanding workaholic reflected in the eyes of those she loves and works with; the scared woman peering beyond the terrifying precipice of cognitive decline over which her disease is sweeping her.

Through this work Genova shines light on the second face of Alzheimer's disease – the minority of cases affecting people under 65 years of age. While both forms of this disease involve the death of neurons vital to memory and cognition, EOAD is distinct from its elder sibling in many ways. EOAD patients are often misdiagnosed, delaying appropriate care for months to years during the window of treatment. There is a strong genetic component to EOAD, meaning that these patients also have a high chance of passing determinant genes to their children. Finally, as EOAD impacts people still in the middle of their lives, their unique set of challenges includes caring for their own elderly parents, managing continuing careers, and even parenting children still at home.

Alice is completely unprepared for her diagnosis of EOAD. In the neurologist's office she watches as a woman

in a chair across the room nods in response to the doctor's counsel. It is only after the wave of shock breaks that she realizes she is still the woman in the chair, "strangely aware of her hands clenching the cold metal arms of the chair she sat in. Her hands...she'd just been diagnosed with Alzheimer's disease." Thus begins Alice's quest to discover where the path of her new life lies, and who she will become as her brain succumbs to the tangled proteins already choking its synapses.



Alice's biggest fear is that she will lose herself to her disease. She fears the inevitable day when she will have to vacate her corner office on campus, when her opinion will no longer be sought on the nature of language, when she will no longer have classes, seminars or conferences to attend, when she will not recognize her loved ones. Even at the beginning of her illness, Alice foresees the chasm that would open between her and those around her, comparing its insidious course with that of cancer:

With cancer, she'd have something that she could fight. There was surgery, radiation, and chemotherapy. There was the chance that she could win. Her family and the community at Harvard would rally behind her battle and consider it noble. And even if defeated in the end, she'd be able to look them knowingly in the eye and say good-bye before she left.

As Alice and her family begin this new phase of their lives in the shadow of EOAD, she finds her world shrinking. As her disease progresses, her vanishing memories and dwindling vocabulary begin to come between her and her work, her colleagues, her students and her family. Alice's increasing loneliness is palpable as her calendar empties and her ability to cope with many situations decreases, keeping her at home. As Alice lays plans for the precious remaining time allotted to her, she and her husband John must deal with his continuing career and her increasing needs. Alice must cope with the frustrating nature of her situation and her fears in a sometimes alien world. She questions what her place in the

world will be once she is incapable of continuing the career she loves, and taking joy in the life she has worked so hard to build. Alice ultimately wants control over her own life, and struggles with the thought of becoming a burden to her loved ones.

As Alice's work-centered life transforms, she is able to see those around her in a new light, deepening her relationships and reaching out to new kindred even as her disease moves on apace. Many of the roles Alice defines herself by: author, teacher, researcher, are stripped from her one by one. The question of whether the Alice-that-was would be at peace with her transformation remains. The Alice-that-is continues to re-define herself, finding joy and revelation in her life with EOAD. In her own words: "My yesterdays are disappearing, and my tomorrows are uncertain, so what do I live for? I live for each day, I live in the moment... I will forget today, but that doesn't mean that today doesn't matter."

Dr. Genova paints a very clear picture of many of the hurdles that must be faced in early-onset dementia. By necessity this book is a synopsis. For those who live with neurodegenerative disease every day, the vignettes recounted in this story are a blip on the steady course that such diseases must inevitably follow. While the burden of diagnosis, the burden of care, the paucity of treatments are all tragic in their own rights, this story and this disease are worthy of reflection. We do not have the means to cure those who suffer as Alice does, but we have the means to care for them and remember the people they are, waiting on the other side of their disease, sometimes very quietly, and sometimes shining clearly through.